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Solidarity and Solitude: Disrupted Memories of AIDS in the Hemophilia Community

A thesis submitted in partial fulfillment of the requirement
for the degree of Bachelor of Arts / Science in Department from
William & Mary

by

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Accepted for Highest Honors
(Honors, High Honors, Highest Honors)



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Introduction

Why are so many of the other people with hemophilia I know so young?

I'm not entirely sure when this question occurred to me, but I do know that I must have been pretty young when it first crossed my mind. Even in elementary school, I realized that older men were conspicuously absent from the events that my local hemophilia chapter put on. For some events, this absence didn't strike me as particularly unusual. 50 year old men, after all, don't often show up to watch the latest Shrek movie and eat pizza with 10-year-old boys. But if these everyday absences were explainable, the more significant ones were not. Why was it, for instance, that older men were so rare at our chapter's annual meeting? Why did so few of them show up for our annual grassroots advocacy trips to Richmond?

As a child, I had no idea of the trials and tribulations that older generations of people with hemophilia had gone through. I knew that the clotting factor I took to stay healthy was a relatively recent invention, and that life without it was painful and dangerous. I knew that things had changed a lot even during my lifetime, and that I should be grateful to be born when I was. Outside of those basic facts, however, I knew almost nothing about the history of hemophilia. My brother and I were cases of spontaneous mutation, meaning that we were the first ones in the family to have the disease. Like that out-of-nowhere diagnosis, my understanding of hemophilia itself was profoundly de-historicized.

As I grew older, I tried to learn more about hemophilia history. In many ways, this thesis is merely the latest iteration of that long-running project to better understand the experiences of the people who struggled with this disease before I did. When I reached out to those few men who were still alive to learn about the many who were not, I learned that the AIDS epidemic

devastated whole generations of people with hemophilia who might otherwise still be around today. I learned about the various people and institutions that my elders saw as villains responsible for the community's infection, and the various people and institutions they saw as heroes who worked to prevent it. Learning these things helped me understand the hemophilia community's history, but it certainly did not help me see myself in it. If anything, learning these things made me feel *more* convinced that my life was unprecedented, *more* conspicuously aware of just how lucky I was to be born when I was. Although I shared a hemophilia diagnosis with these men, our day-to-day realities were nevertheless separated by an unimaginable divide.

When I began to study this topic, my first forays into the academic literature only confirmed that impression. I came across articles with names like "Hemophilia: An Amazing 35-Year Journey from the Depths of HIV to the Threshold of Cure," which promised even with their titles that the worst was behind us.¹ I came across books like Susan Resnik's indispensable *Blood Saga*, which claimed that people with hemophilia had "emerged from their medical closet and approach the biotech century determined to overcome a painful past and savor a bright future."² But even as I encountered these perspectives, I simultaneously began to notice various continuities in modern hemophilia care that echoed this difficult history. Although I never experienced what it was like to be abandoned by the federal government at the height of a deadly epidemic, I did meet people not much older than me who suffered permanent joint damage because they could not afford expensive clotting factors and received inadequate care at the ER. Although the company I purchased factor from entered the market after the contaminated factor

¹ Gilbert C White, "Hemophilia: an amazing 35-year journey from the depths of HIV to the threshold of cure," *Transactions of the American Clinical and Climatological Association* vol. 121 (2010), 61-75. PubMed PMID: 20697550.

² Susan Resnik, *Blood Saga: Hemophilia, AIDS, and the Survival of a Community, Updated Edition with a New Preface* (Berkeley: University of California Press, 1999), 191.

crisis, I did learn that the corporations which dominated the hemophilia market during the AIDS epidemic got off with a virtual slap on the wrist and continue to make billions of dollars by selling life-saving medicine to desperate patients. And although I never knew what it was like to grow up reliant on a completely unregulated blood supply, I did notice that many of the activists who demanded exhaustive safeguards in the aftermath of the AIDS epidemic now bemoaned the fact that their hard-fought gains were slowly eroding beneath the weight of history.

As I continued to research the contaminated factor crisis, these contradictory perspectives on its ongoing significance came to fascinate me. Had the various abuses and oversights that led to the hemophilia community's mass infection with HIV really been vanquished, or had they merely been pushed beneath the surface of modern hemophilia politics? Confronting that question once again brought me back to the divide between myself and the older men with hemophilia, which seemed insurmountable all those years ago. Upon closer inspection, however, the gap in hemophilia history appeared more tenuous than ever. I began to think of change over time in hemophilia care as part-substantial and part-illusory, and started to interrogate the linear progress narratives that divided the past from the present. Without veering into a total contrarianism that denied all progress, I began to explore the various ways that hemophilia care had *not* changed rather than the ways that it had.

I soon found many more people with hemophilia shared my reservations than I expected. Several of the older men whose experiences I had once thought were so alien disputed that assessment, and told me that they still see echoes of the AIDS epidemic in the modern realities of hemophilia care. Other people my age confessed they also saw certain parallels, though they were always quick to preface their remarks with disclaimers that they obviously appreciated just how many things *had* changed. As I returned to the books and articles that emphasized the

discontinuities in hemophilia care, I realized that many of them did not reflect these deeply held beliefs and reservations that I saw in the community. They were written by relative outsiders to our spaces, who were often closer to the architects of hemophilia care than the recipients. They drew on a set of sources that excluded certain inconvenient voices, and passed over that exclusion in silence. Some of these omissions, these gaps in the archive, were caused by the AIDS epidemic itself, which killed nearly half of all people with hemophilia. Compounding that problem, however, were key actors implicated in the contaminated factor crisis, who rushed into the void left by these absences to impose their own perspectives on the narrative. By burying the hemophilia community's understanding of its own infection beneath layers of "official history," these storytellers have contributed to a distorted recollection about the extent, causes, and aftereffects of HIV in the hemophilia community.

The hemophilia community's cultural memory of AIDS is not the only case of deliberately manufactured, managed, and curated memory. In her book *Gentrification of the Mind: Witness to a Lost Imagination*, Sarah Schulman argues that the historiography of revolutionary AIDS protest organizations like ACT UP has suffered from a similar misapplication of power. As in the story of hemophilia and HIV, institutional history works to transmute the "committed battle of thousands of people, many to their deaths" into a false narrative of America naturally "coming around" without any external pressure.³ As in the hemophilia community, the absence of a fuller history creates a discontinuity in LGBTQ+ spaces, which Schulman describes as "a wall between the two groups."⁴ Finally, as in hemophilia, this deliberate rupture of cultural memory profoundly harms both generations. The

³ Sarah Schulman, *Gentrification of the Mind: Witness to a Lost Imagination* (Berkeley: University of California Press, 2012), 9.

⁴ Schulman, *Gentrification of the Mind*, 10.

incomplete work of ACT UP organizers was first undermined and then obfuscated by reactionary forces that opposed their project, leaving the dead half-forgotten and the living in “a kind of hell of confusion and chaos that feels personal but is actually political.”⁵ The younger generation, by contrast, has been deprived of a full understanding of their history, which in turn limits their perspectives on the current moment. They live in a world that “tells them that things are better than they are,” and stumble forward in relative ignorance of the pitfalls that might lie ahead.⁶

Writing in Schulman’s tradition, I intend this project to chip away at the institutional history that both denies the full impact of the HIV epidemic on the hemophilia community and maintains a wall between successive generations of people with hemophilia. Unlike Schulman, I cannot speak to this history from personal experience. I am a member of the generation that comes after the plague, who has “never been that profoundly oppressed” but has nevertheless “wanted to understand.”⁷ This work therefore argues that the official histories of the AIDS crisis and hemophilia were distorted by applications of power from historians and capitalist self-interested drug companies that took advantage of archival gaps to silence dissent, and that this deliberate obfuscation disadvantages current activism. Working toward that understanding would have been impossible without many of the prior histories on the epidemic that I depart with on certain issues, and as such I want to avoid the urge to overcorrect for institutional bias and swing into total contrarianism. My goal is to take advantage of mainstream histories while always acknowledging the voices that they exclude, reconciling these disparate schools of thought on the epidemic into a more complete whole.

⁵ Schulman, *Gentrification of the Mind*, 9.

⁶ Schulman, *Gentrification of the Mind*, 11.

⁷ Schulman, *Gentrification of the Mind*, 11.

Chapter 1

“A nation’s blood supply is a unique, life-giving resource and an expression of its sense of community.”¹ So reads the first sentence of the American Institute of Medicine’s report *HIV and the Blood Supply*, a retrospective analysis of one of the deadliest iatrogenic catastrophes of the twentieth century. There is more truth in that sentence than its authors may have realized. For millennia, people with the disease hemophilia suffered from their condition with no recourse, until innovations in the blood supply first realized in the 1930s gradually transformed their standard of living. Finally emerging from a time of great adversity and hardship in the 1960s, the hemophilia community achieved an unprecedented level of care and wellbeing, all made possible by blood products like cryoprecipitate and clotting factor. But these innovations were a double-edged sword. Clotting factor was far more susceptible to contamination than anyone realized, and by the 80s antihemophilic medications were hopelessly contaminated with deadly hepatitis and HIV. Industry, government, and community leaders alike all preferred to wait in silence rather than blow the whistle when they learned of the risks, all while people with hemophilia continued to use factor as if nothing was wrong. By the time anyone thought to warn the hemophilia community, it was far too late: more than twelve thousand individuals with hemophilia had already treated bleeds with HIV-contaminated product.

How could this happen? How could a community’s “unique, life-giving resource” turn into the agent of its destruction? Unfortunately, the IOM report raises more questions than it answers. *HIV and the Blood Supply* is provocatively subtitled *An Analysis of Crisis*

¹ Committee to Study HIV Transmission Through Blood and Blood Products, *HIV and the Blood Supply: An Analysis of Crisis Decisionmaking*, Lauren B Leventon, Harold C Sox, Michael A Stoto, eds. (Washington, DC: The National Academies Press, 1995), 1.

Decisionmaking, yet still purports that “This report does not seek to determine liability or affix blame.”² An “Analysis of Crisis Decisionmaking” that obfuscates the decision-makers may be good enough for a safe, political document written to reform policy, but it falls well short of the standards of serious historical inquiry. Yet a true account of how this crisis went unremarked and unaddressed is far more troubling, because it implicates not only specific actors in the world of hemophilia but also the broader American medical system they moved in. In truth, many of the decisions that caused the worst outcomes of the HIV crisis had already been made decades earlier, during hemophilia’s so-called “golden age.” From its very beginnings, the commercial care of people with hemophilia carried within it the seeds of mismanagement that would eventually grow into the HIV crisis. The factor industry is more a product of the pharmaceutical market than an aberration of it, and the HIV epidemic should not be dismissed as a one-time exception in an otherwise ethical and above-board account of hemophilia care in America. More generally, hemophilia care is a microcosm of the broader “world of medicine,” and the tragedies that the hemophilia community experienced during the AIDS epidemic reflect the worst impulses and outcomes that can arise whenever healthcare is treated as a private business rather than a public good.

A Prehistory of Hemophilia and AIDS

Hemophilia is a rare genetic disorder, characterized by an inability to clot. This inability is caused by one or more missing factors, components of blood that bond together to form a complete seal. If any given factor is missing, the chain of proteins will end at that point and clots will not form. Since the blood of a person with hemophilia does not clot properly, that person

² Leventon, Sox, and Stoto, *HIV and the Blood Supply*, vi.

will bleed longer than individuals with a full array of factors, causing even the smallest injuries to become serious concerns when left untreated. The most common “bleeds” (episodes of bleeding which overwhelm a person with hemophilia’s clotting abilities) are joint bleeds. If left untreated, joints bleeds can do permanent damage to a joint by weakening its synovial membrane. The most serious complication, however, is a head bleed, in which the brain itself bleeds out. Permanent brain damage or death is common in such circumstances if treatment is not administered. Although we now understand that hemophilia can affect *anyone*, regardless of sex or gender, past physicians were not aware of this fact. They conceptualized hemophilia as a disease of those assigned male at birth and worked backwards from that assumption, leaving us with a historical record that highlights the experiences of men with hemophilia and obfuscates the experiences of everyone else.

Before the invention of the most rudimentary blood products, life with hemophilia was incredibly painful and short. According to historian and hemophilia advocate Susan Resnick, “most boys with hemophilia died between the ages of twelve and nineteen.”³ The only existing treatment that existed at the time was whole blood. Unfortunately, there was not enough whole blood to meet the needs of the hemophilia population, and most patients had difficulty securing access. Fortunately for people with hemophilia, things began to change around the end of the 30s. In 1937, Dr. Bernard Fantus established the first public blood bank in the United States.⁴ A few years later in a small hospital in South Carolina, a doctor named John Elliott discovered that blood plasma could be used as a potent alternative to whole blood.⁵ But these innovations paled

³ Susan Resnik, *Blood Saga: Hemophilia, AIDS, and the Survival of a Community, Updated Edition with a New Preface* (Berkeley: University of California Press, 1999), 16.

⁴ Susan Resnik, *Blood Saga*, 17.

⁵ Douglas P. Starr, *Blood: An Epic History of Medicine and Commerce* (New York: Alfred A. Knopf, 1998), 95.

in comparison to the changes that came about in the next decade. A war was about to arrive, and with it a complete transformation of the blood industry.

As America geared up to support its ally Britain and eventually to enter the Second World war, the military conscripted hematologists to turn unreliable and unwieldy blood transfusion technologies into lean and battlefield-ready medicines. The wartime Committee on Transfusion reached deep into academia to find suitable candidates to unlock the potential of these therapies, and they struck gold in 1940 when they found Dr. Edwin J. Cohn, a Harvard chemist who was quietly studying the various components of blood. Quickly ensconced into the military and provided with a generous budget, Cohn discovered how to separate liquid plasma into its component derivatives. Cohn's work, as well as that of other doctors touting the benefits of conventional plasma, inspired the military to create a network that could facilitate mass donations of blood. By 1943, the Red Cross collected more than a million pints of blood. And in 1947, Dr. Kenneth Brinkhaus at Chapel Hill demonstrated that Cohn Fraction 1 was rich in a blood component called AHF, a strange substance could control the bleeding of people with hemophilia.⁶

Although Brinkhaus's discovery would eventually transform the world of hemophilia, it would take some time before other doctors realized the potential of his work. A few lucky patients took Cohn Fraction 1, but the vast majority saw doctors who were not hematologists and thus did not receive this technology. In truth, the average American hemophilia patient was better served by the invention of commercially available plasma. By 1956, the American blood system produced over 5 million units of blood.⁷ This blood came from many sources: some of it

⁶ Susan Resnik, *Blood Saga*, 18.

⁷ Susan Resnik, *Blood Saga*, 31.

was public blood given out of civic generosity, but increasingly it was private blood that flowed from for-profit blood banks that sprang up all across America to accommodate the new role that blood played in American medicine. Despite this trend, many people with hemophilia still managed to ensure the blood that went into their product came from local blood drives in the neighborhood.⁸ This became increasingly implausible, however, as America moved away from its WWII belief that blood donation represented a unique form of patriotic service. Private blood banks were far more likely to sell blood that was contaminated with hepatitis, but it barely mattered in the face of shortages. As the years passed, private blood banks exploited the shortage to muscle into hemophilia care, overcoming progressives like Huey Long who hoped to strangle their influence as part of his broader anti-corporate program.⁹

This era also saw the formal beginnings of an institutional “hemophilia community.” In 1948, the wealthy lawyer and “hemophilia father” Robert Lee Henry created the Hemophilia Foundation, which would eventually become the National Hemophilia Foundation (NHF). NHF advocated on behalf of a cohort of patients who were for the most part still too young to advocate for themselves, soliciting increased funding to educate doctors and fund research grants. It also served as a nexus for families, who for the first time could meet others who understood their struggles. Although all these changes were welcome, it’s important not to romanticize this era. Far too many families were still excluded from this community, either by ignorance of its existence or by a color line that remained just as deeply entrenched in hemophilia as in larger American society. But for the first time, there was a network of families that we can identify as

⁸ Steven Pemberton, *The Bleeding Disease: Hemophilia and the Consequences of Medical Progress* (Baltimore: John Hopkins University Press, 2011), 153.

⁹ Steven Pemberton, *The Bleeding Disease*, 164.

an early hemophilia community. Together, they supported one another as best they were able and waited for a brighter future to arrive.

Stanford hematologist Dr. Judith Graham Pool answered the community's prayers in 1965 when she discovered cryo-precipitate (also called cryo), a residue that collected at the bottom of drained bags of plasma and was incredibly rich in clotting factor.¹⁰ Cryo was potent and easy to collect: a small lot could be made from the donations of a single donor, and the largest lots could be constituted out of twenty donors' worth of blood. Almost immediately, the hemophilia community adopted cryo as the new standard of care. As hemophilia patient Glenn Pierce recounted, "With the help of treating bleeding episodes with cryo [I was able] to become a normal walking person who was able to function productively, miss less school, and reach a point where I could go to college and do well."¹¹ But as quickly as cryo was created, it was replaced by a superior technology. Dr. Brinkhaus, working with the support of Hyland Laboratories, discovered a way to make an even more AHF-rich product by distilling the already potent cryo. In 1968, Hyland received a patent for the first clotting factor. The dream of a "miracle cure" had finally been realized.

It is difficult to stress just how important the creation of factor was to the hemophilia community. For the first time, people with hemophilia could run, jump, swim, attend school, even settle down and have kids. Cryo was an impressive accomplishment, to be sure, and a hemophilia community deeply committed to the pursuit of autonomy did amazing things when empowered by the 1965 precipitate. But cryo was injected through a drip bag, usually taking most of a day to administer. It was next to impossible to travel with cryo, and most patients could

¹⁰ Susan Resnik, *Blood Saga*, 40.

¹¹ Susan Resnik, *Blood Saga*, 43.

not even administer it at the house. In contrast, factor came in a box small enough to fit easily in your hand, and a patient could administer it in the home or on the go. Describing his memories of the transition of factor, hemophilia patient Dana Kuhn recalled that “For me to experience Factor was: This is like a miracle drug. We can now be normal!”¹² But factor products were incredibly expensive, often costing tens of thousands of dollars per year in an era where very few hemophilia patients had insurance. NHF and the newly formed factor companies worked overtime to expand access to factor and to create a medical infrastructure of clinics structured around this new treatment. These efforts culminated in Public Law 94-63, a 1975 law that created a network of clinics for people with hemophilia called HTC’s.¹³

Even as all this was happening, the treatment of hemophilia was changing very quickly, in ways that very few patients understood. Factor was so potent it required hundreds if not thousands of donors to contribute to each vial, ending any hope of public blood banks providing the source plasma. To make matters worse, the companies who produced factor preferred much larger batches to maximize efficiency, with the average dose of factor made up of ten to twenty thousand individual donors’ contributions.¹⁴ Susan Resnik argues that this was the end of what social theorist and historian Richard Tiftmuss called “the gift relationship,” an arrangement in which donors, doctors, and patients felt an easy bond to one another, united by shared humanitarian aims and goals.¹⁵ In the new world, hemophilia became a profit-making venture in which the demands of the market tore these interests out of alignment with one another, with disastrous consequences for the patients. In spite of these changes, very few people with

¹² Susan Resnik, *Blood Saga*, 93.

¹³ Steven Pemberton, *The Bleeding Disease*, 194.

¹⁴ Steven Pemberton, *The Bleeding Disease*, 229.

¹⁵ Susan Resnik, *Blood Saga*, 71.

hemophilia understood the risks: factor companies went to great lengths to keep the appearance of a “community-based treatment” in place, often coordinating initiatives through which a family could pay for their product by sponsoring local blood drives.¹⁶

Although relief for a better therapy was the most common response to these innovations, a few members of the hemophilia community did question the new treatment regime. Hemophilia father and Russian historian Bob Massie, for instance, was an early and vocal critic of post-cryo hemophilia care who called for factor to be distributed as a public good rather than a private commodity. Even in 1967, before factor came to market, Massie had met with various doctors researching the therapy and come away from the experience convinced that the product would be prohibitively expensive. Because most physicians researching factor worked for private industry, Massie believed that their employers had little reason to prioritize an affordable product. He instead pinned his hopes on Dr. Johnson, a “shadowy figure” at the Red Cross who was privately developing his own factor product.¹⁷ Despite promising results, however, the Red Cross barely bothered to invest in Johnson’s factor research. According to multiple scientists and government employees that Massie spoke to, the Red Cross was deliberately slow-rolling the development of Johnson’s product because of pressure from Hyland Laboratories, who hoped to patent their own similar product first.¹⁸ Massie was outraged by this allegation and tried to turn the self-sabotaged Red Cross factor therapy into a major scandal in the community, but Hyland brought their product to market before Massie’s accusations gained traction.

¹⁶ Elaine DePrince, *Cry Bloody Murder: A Tale of Tainted Blood* (New York: Random House, 1997), 42.

¹⁷ Robert Massie and Suzanne Massie, *Journey* (New York: Alfred A. Knopf, 1975), 270.

¹⁸ Robert Massie and Suzanne Massie, *Journey*, 279.

Even as other members of the hemophilia community celebrated the launch of the Hyland product, Massie was still hard at work lobbying for NHF to oppose it. At a meeting between NHF, Red Cross, and Hyland representatives where Hyland revealed its prices, Massie was the only voice to speak out in protest. Recounting his conversation with the Hyland representative Mr. Marquart, Massie recalls that “he was talking about sales, I was talking about joints. Sometimes, when I was talking about crippled joints, pain, prophylaxis, and better lives, Mr. Marquart smiled sadly at me and said, ‘Mr. Massie, you’re being mean to me.’ Everyone else sat silent and looked uncomfortable.”¹⁹ Coming away from that meeting, Massie concluded that regular access to factor would remain a pipe dream in America’s capitalist healthcare system. Convinced that only a national system could save people with hemophilia, he rhetorically asked himself “how soon could the American people be persuaded—as every other industrial western people has long ago decided—that health care was a social obligation, that keeping citizens healthy was every bit as important as teaching them to read and write or paying them welfare when they were out of work?”²⁰ When he confronted the question directly, Massie concluded that this day would not arrive in time for his son. He decided to emigrate to France not long after the Hyland meeting, where he hoped his son would receive better care.

Just as privately sourced blood products were more expensive than their public counterparts, they were also more dangerous. This danger was only magnified by the widespread adoption of plasmapheresis, a previously-niche technology in the field of plasma collection that was developed in the early 20th century but only perfected in the 60s to meet increased demand for plasma. Plasmapheresis enabled donors to give blood frequently without the risk of anemia,

¹⁹ Robert Massie and Suzanne Massie, *Journey*, 286.

²⁰ Robert Massie and Suzanne Massie, *Journey*, 281.

thus creating the potential for habitual donors. With older technologies, blood donors could only donate six times a year. With plasmapheresis, they could donate one hundred and four times.²¹ Using this technology, a new coalition of private blood banks quickly built up their own networks all over the country to collect plasma from the most vulnerable and desperate populations, often soliciting donations from prisoners and the homeless. In these communities, blood banks normalized the idea that donors could supplement their income by giving blood, thus attracting donors from populations far more likely to exhibit hepatitis (and later HIV) than the average blood donor.²²

Dr. JG Allen was one of the first scientists to notice the dangers of privately procured blood products and sound the alarm. In 1966, he wrote an article warning that “There are groups among donor populations whose blood produces more cases of icteric hepatitis than other groups. For example, the number of cases resulting from single transfusions when the donors are of the prison-Skid Row variety is 10 times greater than the number of cases resulting when the donors are volunteers, members of the family or friends.”²³ Allen’s analysis of hepatitis-infected donors obfuscated the role that America’s classist, racist healthcare and prison systems played in producing these outcomes, and instead toed the line of depicting hepatitis infection as a *moral* failure on the part of the donors themselves. But he accurately identified the pattern of hepatitis among certain donor populations if not the actual causes of that pattern, and other onlookers quickly took notice. The federal government acknowledged Allen’s warnings around the turn of the decade, and in 1973 the Assistant Secretary of Health published a National Blood Policy that

²¹ Steven Pemberton, *The Bleeding Disease*, 169.

²² Elaine DePrince, *Cry Bloody Murder*, 38.

²³ JG Allen, “Post-Transfusion Hepatitis, a Serious Clinical Problem,” *California Medicine* 104, no. 4 (April 1966): 297, PubMed PMID: 5551310.

admitted “commercial sources of blood and blood components for transfusion therapy has contributed to a significantly disproportionate incidence of hepatitis, since such blood is often collected from sectors of society in which transmissible hepatitis is more prevalent.”²⁴ Despite its mention of “blood components,” the National Blood Policy had nothing to say about specific standards for the sanitation of blood products, or the penalties that manufacturers would incur for violating those standards. People with hemophilia were still unprotected.

The American Association of Blood Banks (AABB), a coalition of private and public blood banks founded in 1947, also enabled the proliferation of unsafe blood products by lowering their own standards and urging other authorities to follow suit. The AABB and its client factor companies lobbied state governments to relax standards of safety and liability for collectors and distributors of blood and blood products, often employing lawyers and lobbyists with little understanding of the underlying risk. For instance, from 1971 to 1976 twenty six states passed legislation creating a higher standard of liability for blood and blood product collectors and producers, often through legislative processes in which the blood bank/product industry was well represented while no one was present to represent the interests and concerns of consumers.²⁵ Using the same arguments they had used to muscle in on the plasma industry, blood banks and factor companies created two separate legal spaces: one for public supplies of blood, which patients received in one-time donations, and one for private supplies of blood and privately procured blood derivatives, which lifetime users like people with hemophilia took to survive.

²⁴ Leventon, Sox, and Stoto, *HIV and the Blood Supply*, 41.

²⁵ Elaine DePrince, *Cry Bloody Murder*, 137.

These “blood shield” theories of legal liability were tested in 1977, when the widow and children of a person with hemophilia named James Fogo sued Cutter Pharmaceuticals for its role in James’s death. Fogo had mild hemophilia and rarely used factor, but during previous dental procedures his physicians had noticed extended bleeding episodes in the mouth lasting as long as two weeks. When Fogo returned to the hospital for the extraction of a tooth, those same doctors recommended that he use a new factor product called Konyne to control bleeding. James died from viral hepatitis that he contracted through Konyne less than two weeks after the procedure, but the court refused to find Cutter liable despite the clear chain of evidence. During the trial, Cutter Laboratories’ expert witnesses “acknowledged that the risk of hepatitis is higher in commercial than in volunteer plasma, and it is also higher where plasma is pooled.”²⁶ The court also found credible evidence submitted by the plaintiffs that “two of the plasmapheresis centers from which plasma was obtained were located in slum areas, and that many persons seen entering and leaving the centers appeared to be unclean, elderly, transients, alcoholics and otherwise debilitated.”²⁷ But despite these facts, the lower court did not find Cutter liable for James’s death and the California First Circuit court of appeals upheld their decision. In their opinion, the First Circuit noted that “Konyne, despite its hepatitis risk, has been instrumental in helping many hemophiliacs with Factor IX deficiencies achieve normal and productive lives.” They also accepted Cutter’s rationale that there was an “insufficient number of volunteer donors” to supply safe plasma for factor, and cited California’s blood shield law in their determination that the use of blood products was for legal purposes a service and not a sale.²⁸ That crucial decision meant that Cutter simply was not liable for Fogo’s death, despite their clear negligence

²⁶ Fogo V Cutter Laboratories, 68 Cal. App 3rd 744 (Ct of Appeal, First District, California, 1977).

²⁷ Fogo V Cutter Laboratories, 68 Cal. App 3rd 744 (Ct of Appeal, First District, California, 1977).

²⁸ Fogo V Cutter Laboratories, 68 Cal. App 3rd 744 (Ct of Appeal, First District, California, 1977).

in procuring safe plasma. The court's ruling was clear: factor companies were not responsible for hepatitis in their products.

These decisions had real consequences. In one painful moment of her harrowing account *Cry Bloody Murder*, “hemophilia mother” and community advocate Elaine DePrince describes a difficult conversation between herself and her husband in the early 70s that underscores the costs of relying so heavily on private contributions. Her husband pointed out a warning label on a vial of factor that states that the factor might contain hepatitis, and worried that perhaps they should seek a different treatment. Elaine replied that her husband should not worry: all three boys had already been infected with multiple forms of hepatitis!²⁹ These infections made DePrince's boys sick for weeks, bloated their livers, and caused them intense stomach pain.³⁰ For thousands of people with hemophilia who would survive AIDS, the hepatitis they were exposed to during this period and the AIDS era would ultimately kill them. Yet what choice did patients have? At that time, hepatitis was not seen as a major risk to the hemophilia community. Hepatitis A and B were believed to be relatively innocuous, while the far more dangerous Hepatitis C and D were merely known as the mysterious “non-A, non-B” Hepatitis virus, and marginalized in discussions of risk. When asked about the risks of hepatitis in 1976, NHF co-medical director Dr. Louis Aledort replied that studies of hemophilia mortality indicated that “Spontaneous bleeding was the major cause of demise, with trauma following closely behind.”³¹ Armed with this data, NHF argued that expanding access to factor was more important than worrying about infection.

²⁹ Elaine DePrince, *Cry Bloody Murder*, 39.

³⁰ Elaine DePrince, *Cry Bloody Murder*, 48.

³¹ Steven Pemberton, *The Bleeding Disease*, 231.

As the decade continued and no retribution came down from regulatory agencies, factor companies became increasingly comfortable acting like the imperial overlords of their new world of hemophilia. At the same Hyland Laboratories where factor had been invented just six years earlier, Dr. Edward Shanbrom noticed in 1971 that the industrial vats of factor were so contaminated that workers who did not even handle the product fell ill with hepatitis. He concluded that the vapors alone were contagious enough to infect his workers. Alarmed, Shanbrom proposed a new program to monitor the health of his employees.³² Hyland initially went along with the program, but discontinued it within two years. Shanbrom resigned in protest, and by the mid to late 70s returned to all four major factor companies with a detergent process for viral inactivation. None of them adopted his technology. Shanbrom also approached the Hepatitis Division of the Centers for Disease Control, but even they were unable to help. According to a letter the CDC sent Shanbrom in response, the organization was so under-funded in the hostile political climate of the late 70s that they did not have the money to test his procedure.³³

Looking back on the history of hemophilia from the creation of the first blood bank to the rejection of Shanbrom's technology, a clear narrative emerges: key breakthroughs in hemophilia treatment only happened when multiple agencies or actors collaborated. Dr. Cohn laid the foundation for cryoprecipitate and factor concentrates when he worked with the U.S. government. Hematologists who returned from their wartime conscription used the new blood bank network they created to supply hemophilia patients with plasma, and people with hemophilia succeeded in creating the HTC network when they came together to form NHF. Dr.

³² Elaine DePrince, *Cry Bloody Murder*, 52.

³³ Elaine DePrince, *Cry Bloody Murder*, 53.

Pool stood on Cohn's shoulders to distill cryoprecipitate from his plasma solution, and Dr. Brinkhaus stood on Dr. Pool's shoulders when he collaborated with other scientists at Hyland to distill her cryo into clotting factor. Through all of this, government, institutions of higher education, the hemophilia community, and private enterprise all played crucial roles. But when other institutions retreated from the task of improving hemophilia care and private enterprise was given free rein, abuses accumulated. Private blood banks flourished even when they were demonstrated to be unsafe, because politicians could not muster the political willpower to close them in the face of blood shortages. Factor companies created a business model that maximized the risk of hepatitis, and wrote their own crooked legislation to avoid liability. People with hemophilia were ill served by all of this, but the risks of this era were too often obscured by the remarkable therapies that it produced.

The men and women who worked in parallel institutions intimately understood these dangers. Dr. Cohn patented his plasma fractions despite an informal prohibition against academics taking such measures because he believed that such an act was necessary to protect his fractions from "mercenary interests."³⁴ Writing in 1974, Dr. Pool characterized the new blood industry that her cryo made possible as "dangerous, expensive, wasteful, and unethical."³⁵ Both have been validated by history. What happened in hemophilia care from 1937 to 1976 alone is argument enough that public health and private business must be separated at all costs. But for the hemophilia community, the worst was yet to come. Private industry had already hollowed out all regulatory checks on the sale of hemophilia medication. The stage was set for a far worse infection.

³⁴ Steven Pemberton, *The Bleeding Disease*, 94.

³⁵ Elaine DePrince, *Cry Bloody Murder*, 42.

HIV Enters the Blood Supply

The story of how government, industry, and community figureheads enabled the infection of the hemophilia community began in January 1982, with a quiet phone call from an unnamed Florida physician to Dr. Bruce Evatt, then Chief of the Host Factors Division at the CDC. The unnamed physician reported that one of his patients with hemophilia had died of pneumocystis pneumonia, and he was worried that the factor supply had been contaminated with pneumocystis. Prior to and then concurrently with his job at the CDC, Evatt had worked in the field of hemophilia care for over 15 years. He could not recall any examples of a hemophilia patient dying from pneumocystis, but he soon discovered a way to check his recollections. Since the Division of Host Factors distributed pentamidine, the only drug that was effective in the treatment of pneumocystis, Evatt was able to compare a registry of the patients whom the CDC had distributed product to against a list of hemophilia patients. No patients matched, but Evatt asked a clerk to keep vigilant for any new requests. By July of that year, two more patients had been infected.³⁶

Even as this was all happening, a larger epidemic was breaking out across the country. In a 1981 CDC *Morbidity and Mortality Weekly Report*, the CDC first noticed the “unexpected occurrence in five young homosexual Los Angeles men of an unusual and often lethal type of protozoan infection of the lung (pneumocystis carinii pneumonia).”³⁷ Quickly dubbed GRID (short for Gay Related Infectious Disease and hence referred to by its proper name AIDS), opinions were divided in the medical community as to what was causing the infection. Writing in the prestigious *Lancet*, some British doctors blamed “poppers” (amyl and butyl nitrates used as

³⁶ Susan Resnik, *Blood Saga*, 116.

³⁷ Susan Resnik, *Blood Saga*, 113.

party drugs and during intercourse). In contrast, an unnamed Harvard physician advanced a more conventional American position when he wrote that an “overindulgence in sex and drugs and the New York City life-style” caused the disease—conveniently ignoring the fact that even in 1981 AIDS was known to be an international epidemic.³⁸ Of course, it is impossible for us as historians to put aside hindsight in questions of discovery, but even hindsight cannot explain how so many intelligent men and women missed the potential viral angle. Reflecting on the early response to AIDS in 1986, the CDC’s chief director of the HIV task force argued that “not everyone took it equally seriously at the beginning...I think a lot of it was the perception of the general public, which was echoed by decision makers, that it seemed to be an isolated, unusual problem. It was affecting primarily gay men - there were certainly the undercurrents that gay men deserved it anyway.”³⁹ This willful ignorance would prove deadly to people with hemophilia.

Even as other doctors let prejudice blind them to the risks of AIDS, Evatt quickly realized the significance of an AIDS symptom that appeared in heavy users of the blood supply. On July 5, 1982, Evatt wrote to Dr. Aledort of NHF with grave news: he believed that the entire blood supply was contaminated with some AIDS-causing virus.⁴⁰ Evatt had a good basis for his pronouncements: he had visited both AIDS-infected hemophilia patients, and neither of them seemed to exhibit any of the ordinary risk factors associated with the disease.⁴¹ More worryingly still, each of these three patients was on a different brand of factor, or was at least purchasing their medication from a factory that no other patient in the group purchased from. In other words,

³⁸ Susan Resnik, *Blood Saga*, 114.

³⁹ Susan Resnik, *Blood Saga*, 115.

⁴⁰ Steven Pemberton, *The Bleeding Disease*, 245.

⁴¹ Steven Pemberton, *The Bleeding Disease*, 244.

if factor really was the agent of transmission, then at least three separate lots of factor were contaminated, with each lot supplying anywhere from five hundred to two thousand five hundred unique vials of factor.⁴² Ten days later, Evatt's team published their findings in the July 16th issue of the CDC's *Morbidity and Mortality Weekly Report*, writing that "Although the cause of the severe immune dysfunction is unknown, the occurrence among the three hemophiliac cases suggests the possible transmission of an agent through blood products."⁴³ Evatt immediately presented his findings to the Public Health Service, who quickly established an emergency task force made up of representatives from the CDC, the NIH, the FDA, NHF, and major blood and plasma organizations (including AABB, the four major factor companies, and BPAC, the Blood Products Advisory Committee, which was a coalition of doctors affiliated with private blood product manufacturers who advised the FDA).

Evatt's work was impressively prescient for its time, and had he and like-minded believers in the CDC been taken seriously perhaps the whole history of HIV in America would have unfolded differently. Evatt suggested that the causal agent for AIDS was caused by an infectious agent that could be transmitted through bodily fluids. What's more, he also guessed that the agent was viral and possibly retroviral based on his knowledge of the cleaning standards of factor products.⁴⁴ But despite this dramatic insight, the July 27th meeting accomplished very little. Unhappy with the evidence, other institutions of government and industry refused to heed the CDC line. As Evatt recalls, "Obviously there was a tremendous amount of skepticism, especially on the part of the blood banks, that this was even a real disease and that we were

⁴² Elaine DePrince, *Cry Bloody Murder*, 57.

⁴³ CDC, *MMWR* 31 no. 27, July 26, 1982, in "The Trail of AIDS in the Hemophilia Community" (unpublished manuscript, 1994), IV-2.

⁴⁴ Elaine DePrince, *Cry Bloody Murder*, 56.

alarmist in thinking that three hemophiliacs would be even remotely associated with a blood-borne disease at this time.”⁴⁵ The CDC wanted to screen donors by sexuality, but gay rights groups and factor companies argued that such a decision would represent too drastic a violation of civil rights. Despite these setbacks, the members agreed on three basic resolutions. First, BPAC member companies should attempt to develop techniques to “decrease or eliminate the infectious risks from Factor VII.” Secondly, NHF should inform patients of the scientific consensus on HIV and community advocates from the hemophilia and gay communities should play a central role in further debates. Finally, the CDC would continue to use the sale of pentamidine to track AIDS in hemophilia, as well as create a scientific framework to accumulate data about the immunological competence of uninfected hemophilia patients.⁴⁶

Even as the CDC was documenting the infection of the hemophilia community, BPAC and AABB were hard at work trying to protect their status quo. Although they withheld this information at the July meeting, by 1980 American factor companies had already been offered a viral inactivation process by the German factor company Behringwerke AG. Berwingwerke had even published their findings in a 1981 issue of German journal *Arzneimittel-Forschung*, but it appears that American regulators did not realize this in 1982.⁴⁷ Unknown to Behringwerke or BPAC, the same heat technology that could mitigate hepatitis would also prove indispensable in the fight against HIV. So even as BPAC promised to explore technologies to decrease the risk of infection, BPAC members chose to suppress evidence of a technology’s existence rather than pay for it. Of course, BPAC representatives dispute this version of events. They point to internal

⁴⁵ Susan Resnik, *Blood Saga*, 119.

⁴⁶ Dr. William H. Foege, “Summary Report on Open Meeting of PMS Committee on Opportunistic Infections in Patients with Hemophilia, August 6th, 1982, in “The Trail of AIDS in the Hemophilia Community” (unpublished manuscript, 1994), II-9.

⁴⁷ Elaine DePrince, *Cry Bloody Murder*, 58.

studies they conducted that showed that the resulting product was 90% less effective, even though Behringwerke studies only indicated a 50% loss. The Institute of Medicine indicated in its retrospective report that “the reasons for the discrepancies in the results obtained by different companies in testing this method are not clear.”⁴⁸ Because of these disparities, community advocates like Elaine DePrince have argued that industry manipulated the data to suit their own agenda.⁴⁹ Although these technologies were too primitive to secure the entire blood supply, the fact that major factor companies such as Alpha and Baxter chose to withhold them speaks to how normal it was for these institutions to think of themselves as autonomous policy makers who decided the direction of blood supply regulation (or lack thereof).

Blood banks also did their part to mislead the FDA, launching a massive PR campaign to reassure Americans about the safety of the blood supply. In a February 1983 interview with the *New York Times*, chairman of the AABB Dr. Henry Bove underplayed the risks of AIDS, arguing that he was concerned but reaffirming that “as a scientist, I have to look at the evidence. And the evidence is that ordinary blood transfusions are not transmitting AIDS.”⁵⁰ However, in private Bove took a very different stance. In his concurrent 1983 report to the AABB, he wrote that “the most we can do in this situation is buy time. There is little doubt in my mind that additional transfusion-related cases and additional cases in patients with hemophilia will surface. Should this happen... it will be essential for us to take some active steps to screen out donor populations who are at high risk of AIDS. For practical purposes this means gay males.”⁵¹ Even as Bove privately acknowledged the risk of AIDS in the blood supply and predicted AABB’s

⁴⁸ Leventon, Sox, and Stoto, *HIV and the Blood Supply*, 87.

⁴⁹ Elaine DePrince, *Cry Bloody Murder*, 59.

⁵⁰ Robin Marantze Henig, “A New Disease’s Deadly Odyssey,” *New York Times*, February 6, 1983, <https://archive.nytimes.com/www.nytimes.com/library/national/science/aids/020683sci-aids-mag.html>.

⁵¹ Leventon, Sox, and Stoto, *HIV and the Blood Supply*, 281.

eventual embrace of donor deferral, he publicly dismissed all possible links between blood products and HIV.

Ignorant of these machinations, leaders at NHF moved haphazardly towards a community warning system. Unfortunately, these community bulletins rarely gave information that accurately portrayed the danger that factor products posed. In the *Hemophilia Patient Alert #1*, published on July 19, 1982, Aledort first told the hemophilia community about the CDC's research but emphasized that "the risk of contracting this immune-suppressive agent is minimal (emphasis his) and the CDC is not recommending any change in blood product use."⁵² The stance was probably disingenuous: in the aftermath of the crisis, Evatt and other HIV researchers who worked with NHF like Dr. Don Francis denied ever endorsing the use of factor during the time period over which factor was contaminated.⁵³ From then on NHF issued periodic patient, chapter, and clinic alerts, but they never really caught up to the scientific dangers that the CDC saw in the blood supply. NHF continued to advocate treatment with factor products well into 1984, although they did eventually urge caution for certain populations. For instance, in *Chapter Advisory 14* NHF asserted that "if sexual partners of hemophiliacs are at increased risk for AIDS, this risk is remote," despite the fact that even in 1982 Evatt had predicted that AIDS could easily be transmitted through heterosexual sex.⁵⁴

NHF was ineffective for a variety of reasons. First, the doctors who made up NHF's medical leadership team were not equipped to understand the significance of the epidemiological data that the CDC presented. They were specialists who dealt with patients on an individual

⁵² NHF, "Hemophilia Newsnotes: Hemophilia Patient Alert 1," July 14, 1982, in "The Trail of AIDS in the Hemophilia Community" (unpublished manuscript, 1994), II-12.

⁵³ Elaine DePrince, *Cry Bloody Murder*, 70.

⁵⁴ NHF, "Hemophilia Information Exchange: AIDS Update, Chapter Advisory 14," February 3, 1984, in "The Trail of AIDS in the Hemophilia Community," (unpublished manuscript, 1994), II-147.

basis, and for the first few months of the epidemic they had difficulty putting aside anecdotal evidence from their own populations and thinking about the holistic health of the community.⁵⁵ Second, leadership in NHF had worked to achieve the dream of “normalcy” for decades, and each additional advance had only been made possible through their decision to embrace new therapies. Aledort, for instance, had pioneered the concept of the “integrated care” model of hemophilia clinic in his home state, where he helped patients achieve access to the factor that let them climb out of wheelchairs and throw away crutches and braces.⁵⁶ In the same vein, patient leaders at NHF were also reluctant to believe that the “miracle drug” that had enabled their new lifestyle had become a delivery system for one of the most deadly complications that the community would ever face. NHF board member Charles Carman, for instance, grew up with hemophilia at a time before cryo, and still remembered the days when boys like him were told that they “should not venture out of that house.”⁵⁷ No one who had lived through that era wanted to go back to the “bad old days” of hemophilia care, and Carman’s plea for CDC investigators not to “take this stuff [blood and factor VIII concentrate] away from us” reflected that deeply held priority.⁵⁸ Finally, NHF increasingly relied on factor companies for financial support, and was reluctant to bite the hand that fed them. NHF essentially adopted some of the pharmaceutical companies’ attitudes for their own, fooled into a misguided belief that they still shared common interests. Describing the ideology of NHF, Resnik writes that “by 1983, viewing blood as ‘a product’ within an economic framework was a given.”⁵⁹

⁵⁵ Susan Resnik, *Blood Saga*, 120.

⁵⁶ Douglas P. Starr, *Blood*, 269.

⁵⁷ Steven Pemberton, *The Bleeding Disease*, 145.

⁵⁸ Donald Francis, Merle Sande, and John Ziegler, “The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984, Volume IV,” transcript of an interview by Sally Smith Hughes conducted in 1993 and 1994, AIDS Epidemic in SF Oral Histories, The Bancroft Library Oral History Center, The Bancroft Library, available at <https://oac.cdlib.org/view?docId=kt729005cr&query=&brand=oac4>.

⁵⁹ Susan Resnik, *Blood Saga*, 131.

When Carman urged the CDC not to intervene on the hemophilia community's behalf, he claimed that "We know it's risky; we're willing to take the risk."⁶⁰ In truth, however, people with hemophilia who knew the true extent of the CDC's projection of HIV in the blood supply were few and far between. At this early stage of the epidemic, most patients who did know about the risk of clotting factor learned that information from alert healthcare providers. In Philadelphia, for instance, Nurse Practitioner Regina Butler heroically stepped into to create a donor cryo program for families who heard news of the dangers of clotting factor.⁶¹ In Ohio, Dr. Ratnoff compared the outcomes between patients who heeded his warnings to adopt cryo and those who stayed on factor, eventually publishing his findings and sounding the alarm that factor was far more deadly than its primitive counterpart.⁶² But figures like Butler and Ratnoff were the exceptions to the rule, and they faced an uphill battle in their mission to change patient behavior. Ratnoff, for instance, immediately told ten of his patients about the risks of HIV when he first heard the news. As he later recalled, five of those patients immediately switched to cryo and five of them shrugged off his recommendations. One of Ratnoff's unconcerned patients told the doctor that he was "messing with my lifestyle," and the Ratnoff's colleagues privately called him "hopelessly old-fashioned and conservative" for even broaching the topic in the first place.⁶³ For the most part, doctors and patients did not change their behavior, and instead followed the medical establishment's misguided recommendations.

⁶⁰ Francis, Sande, and Ziegler, "The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984, Volume IV."

⁶¹ Susan Resnik, *Blood Saga*, 123.

⁶² Susan Resnik, *Blood Saga*, 132.

⁶³ Michael McLeod, "Bad Blood," *Orlando Sentinel*, December 13, 1993, <https://www.orlandosentinel.com/news/os-xpm-1993-12-19-9312270549-story.html>.

As the infection toll continued to mount, Evatt continued to press the issue of a viral basis for AIDS. In October, the MASAC NHF committee was expanded to include the chairpersons of other NHF committees. Regina Butler, the chair of the Nursing Committee, recalled that this meeting was a turning point in her appraisal of HIV, saying that it was “the exact moment when I thought— ‘Oh my god, this is it. This is a horrible thing, and it’s going to kill our patients.’”⁶⁴ Eight hemophilia patients with AIDS had been identified by the winter of 1982, lending credence to Evatt’s theory. More disturbingly, the disease was spreading into the broader blood supply. In San Francisco, a baby died of AIDS two years after receiving multiple transfusions of blood. When the Irwin Blood Bank reviewed their records to find the sources of the contaminated blood, they noticed that one of their donors was a gay man who had already died of AIDS.⁶⁵ These two data points satisfied Evatt. He was sure that some virus in blood was at work in these AIDS infections, and began preparations for another summit in January.

At the January 4, 1983 meeting, the CDC documented the full extent to which the blood supply was contaminated. Speaking on behalf of the CDC, Dr. Tom Spira revealed an exciting breakthrough—working with the Irwin blood bank, the CDC had demonstrated that the anti-HBC (hepatitis B) antibody could serve as a surrogate or proxy test for HIV. According to the CDC, their research indicated that 90% of AIDS victims also exhibited Hepatitis B antibodies that they had developed through past exposure.⁶⁶ The CDC thought that blood banks and factor companies would embrace this technology, but in fact the blood supply was so contaminated that adopting such screenings would be nearly impossible. Many industry insiders also worried about questions of cost, which they asserted that the CDC undervalued: after all, the testing cost

⁶⁴ Susan Resnik, *Blood Saga*, 122.

⁶⁵ Douglas P. Starr, *Blood*, 270.

⁶⁶ Douglas P. Starr, *Blood*, 271.

money.⁶⁷ Gay rights groups also rejected donor deferral and testing, comparing both to “miscegenation blood laws” and “the World War II rounding up of Japanese Americans.”⁶⁸

Predictably, these meetings accomplished little. NHF President Louis Aledort went along with the factor companies, who tried to appease the CDC by implementing the cheaper donor screening while avoiding the costly Anti-HBC test. Once again, experts in different fields had difficulty speaking to one another: John Hink wrote a memo in the aftermath of the meeting claiming that “experts in other fields paid little attention to these overviews [of hemophilia]... for instance it became obvious that few people understood, or cared about the differences between blood and plasma collection regulations or procedures.”⁶⁹ The FDA refused to use their regulatory authority to recall factor, preferring to endorse the conclusions of BPAC and privately taking the stance that the CDC was manufacturing false controversy in order to avoid funding cuts.⁷⁰ The Red Cross adopted a similar position, arguing in a privately circulated memo that “Even if the evolving evidence of an epidemic wanes, the CDC is likely to continue to play up AIDS—it has long been noted that CDC increasingly needs an epidemic to justify its existence.”⁷¹ Outraged by the obvious skepticism and pushback that the CDC’s recommendations elicited, Dr. Don Francis of the CDC’s hepatitis lab erupted into a rant that has since become famous within the hemophilia community. Banging his fist on the table, Francis shouted “How many people have to die? Is three enough? Is six? Is ten? Is a hundred enough? Just give us the number so we can set the threshold!”⁷² Despite the outburst, nothing final was

⁶⁷ Elaine DePrince, *Cry Bloody Murder*, 115.

⁶⁸ Susan Resnik, *Blood Saga*, 126.

⁶⁹ John Hink, “AIDS Meeting on Jan 4th at CDC Atlanta,” January 6, 1983, e-mail message to Dr. K. Fischer et. al., in “The Trail of AIDS in the Hemophilia Community,” (unpublished manuscript, 1994), II-47.

⁷⁰ Leventon, Sox, and Stoto, *HIV and the Blood Supply*, 126.

⁷¹ Dr. Cumming, “Dr. Katz’s 1/26/83 AIDS Memo,” February 6, 1983, e-mail message to Mr. de Beaufort, in “The Trail of AIDS in the Hemophilia Community,” (unpublished manuscript, 1994), II-80.

⁷² Douglas P. Starr, *Blood*, 273.

decided at the January conference. Reporting back to his supervisors in the aftermath of the meeting, Francis wrote “for hemophiliacs I fear it might be too late. If the T-4/T-8 prevalence data collected to date are reflective of pre-AIDS, 1/3 to 1/2 of hemophiliacs might already be exposed.”⁷³

The failure of the blood banks and factor companies to adopt the CDC protocol at the January meeting normalized a level of dysfunction, denial, and corruption that would come to epitomize this late era of AIDS in the hemophilia community. The CDC continued to push the issue of HIV-contaminated factor products throughout this period, but ultimately the FDA was the only agency with the power to intercede. 1983, 1984, and 1985 were lost years, in which the FDA disregarded the data of the CDC and instead hitched its cart to the policy proposals of BPAC. In one of the most sharply worded critiques in an otherwise bloodless report, the IOM commission concluded that “BPAC did not have the social, ethical, political, and economic expertise necessary to understand fully the ramifications of the decisions it was making. Furthermore, given how much authority FDA in effect has ceded to this advisory group, it did not sufficiently represent all potentially affected groups.”⁷⁴ A less generous interpretation might instead indicate that BPAC was little more than a proxy for the interests of factor manufactures, and that by adhering to BPAC’s recommendations so closely the FDA essentially let the fox into the hen-house.

Because of the FDA’s lax approach to their regulatory duty, there was almost no pressure on the factor industry to reform during these years. In late 1983, FDA-NIH investigators

⁷³ Donald P. Francis, “Opportunities for Eliminating Blood Donors at Risk for Transmitting AIDS,” January 6, 1983, e-mail to Dr. Jeff Kaplan, in “The Trail of AIDS in the Hemophilia Community,” (unpublished manuscript, 1994), II-45.

⁷⁴ Leventon, Sox, and Stoto, *HIV and the Blood Supply*, 126.

announced that they believed antigen testing and heat treatment could eliminate all risk of HIV, and offered a non-binding recommendation that factor manufacturers adopt these protocols.

Reporting back to his superiors in the aftermath of that meeting, Steve Ojala of Cutter Pharmaceuticals wrote “Mike Rodell of Armour [a factor company] proposed a Task Force to deliberate the details of the [FDA’s] recommendation and provide further information in 3 months... The general thrust of the task force is to provide a delaying tactic for the implementation of further testing.”⁷⁵ There is no evidence that the FDA offered any pushback to this “delaying tactic.” The FDA did not do much of anything, in fact, until 1985, when it finally used its regulatory authority to demand that factor companies quietly recall their product. Even at this late date, factor companies continued to look for any angle to offload their remaining non-heat-treated factor. In a 1986 memo, an unnamed Cutter senior manager ordered that the company get rid of its remaining untreated factor by selling it in Japan and Costa Rica, writing that “our current policy for handling the unscreened inventory is to clear our pipeline through normal sales [in these regions]... we need the unscreened inventory to meet our 1986 sales requirements and want to avoid large writeoffs.”⁷⁶

Amazingly, the National Institutes of Health announced that they had discovered HIV before the factor companies even implemented anti-HBC testing, let alone discovered the high-quality detergent and heating processes they had promised. Speaking on behalf of Health and Human Services in 1985, HHS Secretary Margaret Heckler proclaimed that “Those who have disparaged this scientific search—those who have said we weren’t doing enough—have not

⁷⁵ Christopher Waage v Cutter Pharmaceuticals, 926 P.2d 1145 (Alaska Supreme Court, Alaska, 1996).

⁷⁶ Corey Dubin, “Testimony before the NAS/IOM Investigation: HIV and the Blood Supply,” September 12, 1994, in “The Trail of AIDS in the Hemophilia Community,” (unpublished manuscript, 1994), VIII-19.

understood how sound, scientific research proceeds.”⁷⁷ It was little consolation to the hemophilia community. Later that year, factor companies would begin heating their product and testing for Anti-HBC antibodies, at last coaxed into action by the strides in technology that the CDC made while studying heat-treated factor.⁷⁸ The move came too late for most, however. By 1985, more than 12,000 individuals with hemophilia had already been infected.

If a nation’s blood supply is truly a “unique, life-giving resource and an expression of its sense of community,” then that nation must treat its blood supply like a precious treasure and protect it from outside actors who would pervert it towards their own ends. That was the harsh wisdom that this new hemophilia community had lost so much to learn. From the 40s to 80s, the American government and society gradually defaulted on their promises to defend and uphold the safety of the nation’s blood supply, and in their absence private actors sprang up to abuse this life-giving resource. From the beginnings of the private blood bank system, industry served people with hemophilia poorly whenever it came untethered from government regulation and lost sight of the greater good. And as the “gift relationship” crumbled and public support for the hemophilia community weakened, private interests became more and more eager to treat people with hemophilia as a source of profit rather than as a vulnerable population deserving of aid. Hemophilia patients lost their safety as they took on economic value, and in the end inevitable exploitation followed, culminating in the FDA’s unerring devotion to the profit-motivated decisions of BPAC even in the face of an incipient epidemic.

⁷⁷ Douglas P. Starr, *Blood*, 299.

⁷⁸ Susan Resnik, *Blood Saga*, 134.

During the so-called “golden era” of the 70s, the old bywords of hemophilia care were “autonomy” and “normalcy.”⁷⁹ But the AIDS epidemic changed all of that, inspiring a new generation of people with hemophilia to rebel against the system that enabled their infection by adopting a new byword of “self-advocacy.” Despite the political conflicts and scandals of the past two decades, up until this point patients broadly understood NHF, their doctors, and even their factor companies as friendly institutions who served their interests. Now they found themselves in a strange new world, surrounded by dying peers, confronted by doctors who knowingly prescribed them dangerous medications without discussing the risks, and stymied by an NHF so eager to salvage its own reputation that it offered to act as an expert witness against members of the community who sued factor companies.⁸⁰ Perhaps more importantly, thousands of people with hemophilia were dying and the world would not even acknowledge who was at fault. Working against the very institutions that they once believed sustained them, a new generation of people with hemophilia fought for justice for the dead and compensation for the living even as they also struggled to survive AIDS and confront the stigma that accompanied the deadly disease.

⁷⁹ For a discussion of normality as an ideal in the pre-AIDS hemophilia community, see Pemberton’s *The Bleeding Disease*.

⁸⁰ Duncan Barr et. al. to Sherman Fein, November 8, 1985, in “The Trail of AIDS in the Hemophilia Community,” (unpublished manuscript, 1994), II-159.

Chapter 2

It took time for the hemophilia community to fully grasp the scope of the injury that had been done to them. HIV is a disease with a long, long incubation period, meaning that many people with hemophilia went years without realizing their HIV status. It is also a disease with an enormous stigma that was even more daunting during those early days of the epidemic, meaning that many of them did not feel comfortable telling other members of the community about their infection. Finally, the backroom decisions that created the potential for HIV in factor products were still mostly unknown in 1985, and these lurid facts only came to light after years of investigative journalism and litigation. These facets of the hemophilia community's infection with HIV delayed a grassroots response to the epidemic, but they did not prevent it altogether. Over the course of the late 80s and early 90s, disgruntled Americans with hemophilia slowly came together to create new institutions and organizations capable of addressing aspects of the epidemic that they believed previous institutions had ignored. The men and women who made these demands held that existing stakeholders in the world of hemophilia had failed to hold the wrongdoers responsible for the epidemic to account or even uncovered those actors in the first place, and they were prepared to sacrifice their anonymity in order to secure closure and justice for the community. By stepping out of the shadows and revealing their HIV status, they forced the world to reckon with previously under-examined questions of complicity and justice: who was responsible for their infection, and what remedy should America adopt to set things right?

But even as these critics demanded answers, there were other actors in the world of hemophilia who preferred that these questions not be broached in the first place. The same factor

companies, doctors, and professional advocates who many people with hemophilia believed enabled the epidemic were also some of the first figures and institutions to chronicle it, and in so doing they created an “official story” narrative of hemophilia and HIV that obfuscated their complicity and depicted the hemophilia HIV epidemic as an unavoidable tragedy. People with hemophilia who held these groups and individuals responsible for their circumstances faced a real obstacle, then: in order to secure recognition and justice, they would first have to successfully dispute this “blameless” explanation for the ubiquity of tainted blood products in the treatment of hemophilia. They rose to this challenge by waging an ideological war on the factor companies and their enablers, charging these stewards of the community with dereliction of duty in order to fight for justice and reform in a world that was largely unsympathetic to these transgressive, anti-capitalist critiques and demands.

Early Responses to AIDS in the Hemophilia Community

The first attempts by members of the hemophilia community to win compensation or recognition for their injury were unsuccessful. On November 5, 1985, for instance, the law firm of Fein, Schulman, Resnic, Pearson & Esmond served Cutter Laboratories with notice that they planned to file litigation on behalf of the estates of three men with hemophilia who had contracted HIV through Cutter clotting factor. The firm attempted to wield the threat of a PR disaster in order to compel a settlement, writing “we recognize the advantages of an expeditious, equitable, and discrete resolution of these claims, and look forward to a timely and productive response from Cutter and its liability insurer.”¹ Despite these threats, however, Cutter proved unreceptive. Their in-house lawyers conceded that “we sympathize with the families of these

¹ Sherman Fein to Cutter Laboratories Inc., November 5, 1985, in “The Trail of AIDS in the Hemophilia Community” (unpublished manuscript, 1994), II-158.

unfortunate individuals” but went on to write that these litigants “benefited greatly, throughout their entire lives, from the product manufactured by Cutter... which allowed these unfortunate hemophiliacs to live as close to a normal life as possible.”² Cutter’s counsel argued that their client had done everything in its power to create a safe product, noting that “the AHF manufactured by Cutter was done so in strict compliance with all of the requests, guidelines, and demands of the National Hemophilia Foundation, which looks after the interests of the hemophiliacs of this country.” Cutter’s lawyers felt confident that expert hematologists would certainly back up their version of events, warning that “should litigation ensue, I am certain that you will find that the leading hematologists in this country will be acting as experts on behalf of Cutter Laboratories. In fact, should litigation be commenced in your area, the current Medical Director of the National Hemophilia Foundation will act as an expert witness on behalf of Cutter.”³ Protected by this expert consensus that Cutter was blameless, their lawyers ended their letter to plaintiff’s counsel by reiterating their sympathy for the Puerto Rican families but nevertheless concluding that “absent some truly unusual situation, there will not be, and cannot be, any settlement of your cases.”⁴

Pharmaceutical corporations like Cutter had good reason to dismiss the threat of a PR disaster over contaminated clotting factor products in 1985. Many people with hemophilia still accepted that factor was a “miracle cure” that enabled them to live “normal lives,” and viewed HIV as an unavoidable cost of that therapy. Even in 1985, NHF’s president Alan Brownstein maintained that “despite the understandable fear that people have about AIDS, under no

² Duncan Barr et. al. to Sherman Fein, November 8, 1985, in “The Trail of AIDS in the Hemophilia Community,” (unpublished manuscript, 1994), II-159.

³ Barr et. al. to Fein, November 8, 1985.

⁴ Barr et. al. to Fein, November 8, 1985.

circumstances should they abstain from using clotting factor... The risk of not using clotting factor is greater than the risk of AIDS itself.”⁵ Reflecting on her 15 year old’s son’s HIV diagnosis that same year, one mother interviewed by the Boston Globe despaired that “It’s not as though they had a choice whether to take the medication... Either you take it or you bleed to death.”⁶ Many HTC hematologists, reluctant to admit to themselves just how many of their patients had already contracted the virus, sugar-coated the results of the new ELISA test and told people with hemophilia and their families that a positive HIV test did not inevitably mean an eventual diagnosis of AIDS. As a result of their reticence, many community members who would later come to blame the factor companies for their AIDS did not even realize that they were infected during those early days. Hemophilia mother Elaine DePrince, for instance, was in 1986 “reassured by my hematologist that an HIV-positive test result meant only that the virus had passed through a patients system and he had developed antibodies to it and, therefore, immunity.”⁷ Armed with that knowledge, she told a local TV anchor that “as a mother of sons with hemophilia, my greatest fear is that my children will be hit by a car. They stand a greater chance of dying in an accident than of AIDS.”⁸ Unbeknownst to her, all three of her boys with hemophilia had already contracted the virus, and all three would ultimately die of the disease that she confidently asserted her family had no reason to fear.

In 1986, people with hemophilia had many reasons to reject their status of AIDS victims. The lack of good information about the link between HIV and AIDS made it possible for

⁵ Richard A Knox, “Hemophilia and AIDS – A Dilemma; Therapy That Allows Normal Life Exposes Victims to Deadly Virus,” Boston Globe, May 27, 1985, <https://search-proquest-com.proxy.wm.edu/docview/294319514/B5BA0E2102AD4334PQ/>.

⁶ Knox, “Hemophilia and AIDS – A Dilemma.”

⁷ Elaine DePrince, *Cry Bloody Murder: A Tale of Tainted Blood* (New York: Random House, 1997), 79.

⁸ Elaine DePrince, *Cry Bloody Murder*, 79.

members of the hemophilia community to grasp onto a comforting possibility that they would survive the larger epidemic, and that innate bias towards believing in one's self-preservation was certainly the most significant reason that so many people with hemophilia remained sanguine in the face of HIV. But the political context of the times also mattered to their calculus: in 1986 many Americans still viewed AIDS as a "degenerate" disease, the sole province of sinners who had brought illness upon themselves through homosexual sex. HIV/AIDS historian Richard McKay argues that this tendency is not new, citing a broad array of past epidemics to demonstrate that religious right leaders like Jerry Falwell who named AIDS "a gay plague" and a "definite form of the judgment of God upon a society" acted in the tradition of a "long history underpinning the impulses to trace contagion, harbor suspicion, and lay blame in times of epidemic."⁹ Although gay men were the primary targets of this reactionary ire, McKay argues that AIDS itself had become so intimately connected with ideas of complicity and degeneracy that other vulnerable groups who contracted the virus could be smeared by association. As social theorist Cindy Patton put it, once "perceptions of HIV risk were linked to social deviance, literally anyone or any category of people deemed epidemiologically significant could be converted into nominal queers."¹⁰ Although many people with hemophilia still harbored homophobic attitudes or even blamed gay men for their infection during this time, they still acknowledged the bizarre ways that society conflated them with gay men. Reflecting on the response his AIDS diagnosis elicited in 1987, one person with hemophilia complained that "people just hate the gay people...that spills over to the rest of us who have AIDS, too. If you're

⁹ Richard A. McKay, *Patient Zero and the Making of the AIDS Epidemic* (Chicago: University of Chicago Press, 2018), 43.

¹⁰ Cindy Patton, *Last Served? Gendering the HIV Pandemic* (London: Taylor & Francis, 1994), 19.

dying with cancer, you're a heroic person. If you have AIDS and you're dying, even as a hemophiliac, you're kind of the scum of the earth."¹¹

To make matters worse, the same ignorance that led people with hemophilia to reject the idea of an HIV-AIDS link also drove the broader American public into a fervor of AIDS paranoia that only made people with hemophilia more reluctant to disclose their diagnosis. Often referred to as "Afr-AIDS" by its critics, this fear of AIDS soon came to dominate discussions about political responses to the epidemic. In 1986, for instance, conservative firebrand William F. Buckley wrote an editorial in the *New York Times* titled "Crucial Steps in Combatting the AIDS Epidemic." Buckley used his op-ed to fret that there was still no clear consensus on the transmissibility of AIDS, noting that "the moment has not yet come when men and women of science are unanimously agreed that AIDS cannot be casually communicated."¹² He went on to allow that "If the news [about transmission] is progressively reassuring, public identification would not be necessary" while also warning that "If it turns in the other direction and AIDS develops among, say, children who have merely roughhoused with other children who suffer from AIDS, then more drastic segregation measures would be called for."¹³ In Buckley's mind, even the most reassuring picture of AIDS' virulence still called for drastic impositions on civil liberty; he called for the state to issue marriage licenses to people with HIV or AIDS "only after the intended spouse is advised that her intended husband has AIDS, and agrees to sterilization," and wrote that even in the absence of public identification, people with AIDS should be forced to

¹¹ Jane Meredith Adams, "Some Refuse to Give Up Hope," *Boston Globe*, May 17, 1987, <https://www-proquest-com.proxy.wm.edu/docview/2074589128/fulltextPDF/DC8A38594D554ACDPQ>.

¹² William Buckley, "Crucial Steps in Combatting the AIDS Epidemic; Identify All the Carriers," *New York Times*, March 18, 1986, <https://www.nytimes.com/1986/03/18/opinion/crucial-steps-in-combating-the-aids-epidemic-identify-all-the.html>.

¹³ Buckley, "Crucial Steps in Combatting the AIDS Epidemic."

submit to a *private* identification scheme in which “Everyone detected with AIDS should be tattooed (sic) in the upper forearm, to protect common-needle users, and on the buttocks, to prevent the victimization of other homosexuals.”¹⁴ Though these remarks were perhaps extreme in the reactionary discourse about AIDS, they serve to demonstrate just how terrified the broader public really was about the prospect of this “degenerate” disease spreading to other populations.

Generally, the hemophilia community was ill-prepared to face the stigma that an AIDS diagnosis provoked. Many families responded to the daunting prospect of an AIDS diagnosis by remaining in a “medical closet” of sorts, unwilling to admit their own infection to others or even to themselves. Elaine DePrince, for instance, refused to test her sons for HIV when her hematologist first broached the subject in 1986. Even though Elaine still held onto hope that a diagnosis of HIV did not inevitably lead to a diagnosis of AIDS, she also realized that even a recorded diagnosis of HIV could seriously harm her family. She remained firm on her commitment to not test until 1988, when she found a new hematologist for her children who “understood the possible discrimination we would encounter if the results of their HIV tests fell into the wrong hands.”¹⁵ Another person with hemophilia named David LePage recalled that when he was first diagnosed with HIV he “wasn’t afraid to tell anybody about HIV or its complications, so I told my landlord. They forced me out of the apartment. I found another apartment, and by then I had learned not to tell my landlord. I learned that honesty wasn’t the best policy.”¹⁶ These experiences of discrimination and backlash were relatively foreign to the

¹⁴ Buckley, “Crucial Steps in Combating the AIDS Epidemic.”

¹⁵ Elaine DePrince, *Cry Bloody Murder*, 80.

¹⁶ Laura Gray and Christine Chamberlain, eds., *The Gift of Experience: Excerpts from Conversations with 21 Men with Hemophilia, and their Caregivers* (Brunswick: Camden Writers, 2007), 213.

hemophilia community, and they kept many HIV-infected patients from speaking out about their experiences.

Not all hemophilia families shied away from acknowledging their AIDS status, however. Hemophilia father Bob Massie responded to Buckley's editorial with his own furious letter to the editor, where he wrote that sterilization and forced tattooing were "Nazi idea(s) for keeping track of undesirables marked for destruction."¹⁷ Massie concluded his letter by admitting his family's connection to AIDS and rejecting all calls to discriminate against people like his son, writing:

My son is a hemophiliac, one of the groups that, Mr. Buckley says coyly, is at 'special risk.' He goes on to announce that some AIDS carriers will die quickly, and others will live a normal life span. That is my understanding also. But there is another group of people who will not live out a normal life span: these are the people who will try to sterilize or tattoo my son or any other hemophiliac. I will see to that myself.¹⁸

Although the limits of his solidarity only extended to the outer boundaries of the hemophilia community, Bob Massie's letter serves as an early example of the militant approach to advocacy that would eventually characterize the hemophilia community's revolutionary response to AIDS.

Massie's militant approach to the world was necessary in large part *because* of the hatred and discrimination that HIV-infected people with hemophilia received from the broader public. The Ray family in Arcadia, Florida, for instance, quickly found themselves ostracized from their community once Louise Ray confided to her pastor that all three of her boys had contracted HIV through contaminated factor products in 1987. Her pastor responded by offering the family a one-time "love offering" and telling them to stay away from the Church; the school quickly

¹⁷ Robert Massie, "AIDS Needs Medical, Not Emotional Solutions; 'Special Risk,'" *New York Times*, March 27, 1986, <https://www.nytimes.com/1986/03/27/opinion/l-aids-needs-medical-not-emotional-solutions-special-risk-982286.html>.

¹⁸ Massie, "AIDS Needs Medical, Not Emotional Solutions."

followed suit once it learned of the Ray boys' infection, telling the family that their children were not welcome on school grounds before reluctantly offering to build a portable classroom on the blacktop for the three boys to study in complete quarantine.¹⁹ Undaunted by the fierce opposition, the Ray family took their case to court and ultimately won the right to send their children to school. Their time in Arcadia proved to be short-lived, however: the Rays' neighbors responded with a massive school boycott and a campaign of anonymous harassment, which ultimately culminated in a still-unknown arsonist burning down the Rays' home.²⁰ Standing in front of the office of their lawyer in Sarasota the next morning after the attack, the boy's father Clifford Ray told reporters that "Arcadia is no longer our home. They made that very clear to us last night."²¹ Despite their best efforts, the Rays had been forced to leave the town that their children had called home for their entire lives.

Although the socio-political climate surrounding AIDS in America made it difficult for American people with hemophilia to reveal their infection or demand justice, the epidemic's precise unfolding in other parts of the world gave other populations with hemophilia more opportunities for disclosure and advocacy. In Japan, for instance, people with hemophilia were some of the first people to contract HIV through their use of American-made clotting factor, and remained the largest at-risk groups for HIV throughout the first few years of the disease's existence in their country.²² The fact that most Japanese people with HIV contracted the disease

¹⁹ Michael McLeod, "The Outcasts: for the Ray Brothers, Facing AIDS isn't the Worst Part. Living in Arcadia, Florida is," *Sun Sentinel*, (Fort Lauderdale, FL), August 23, 1987, <https://search-proquest-com.proxy.wm.edu/docview/389557640/CF2447B85332450BPQ/2?accountid=15053>.

²⁰ New York Times Regional Newspapers, "Family in AIDS Case Quits Florida Town After House Burns," *New York Times*, August 30, 1987, <https://www.nytimes.com/1987/08/30/us/family-in-aids-case-quits-florida-town-after-house-burns.html>.

²¹ New York Times Regional Newspapers, "Family in AIDS Case Quits Florida Town After House Burns."

²² Fred Hiatt, "Tainted US Blood Blamed for AIDS' Spread in Japan," *Washington Post*, June 23, 1988, <https://www.washingtonpost.com/archive/politics/1988/06/23/tainted-us-blood-blamed-for-aids-spread-in-japan/9e77b478-1183-46e1-a4d0-a4ee3ec7a87d/>.

through clotting factor changed the country's perception of the condition, so Japanese people with hemophilia and HIV were afforded some space to speak out that was denied to their American counterparts. Japanese people with hemophilia were also quick to realize that they were sold American clotting factor long after those same products were banned in domestic markets, which sped up the anti-pharmaceutical backlash and provoked widespread sympathy. As a result of all these factors, Japanese people with hemophilia were some of the first recipients of contaminated blood products to openly accuse the manufacturers of wrongdoing. One anonymous Japanese person with hemophilia interviewed about his AIDS status in 1986 told the *Washington Post* that "I cannot forgive that they (American factor companies) continued selling to Japanese people what had been forbidden to sell to Americans... I think they are very responsible for the spread of AIDS throughout the world, including to me."²³

Institutional hemophilia organizations also stepped forward to fight for justice and compensation in Japan. Yukio Yasuda, the head of the Japan Hemophilia Society, told reporters in the same article that over-reliance on American blood products had turned Japan into "the vampire of the world."²⁴ Yasuda bitterly noted that "For American exporters, it (the sale of factor products) is a very profitable business," before predicting that "As the number of victims begins to grow, so too will the anger."²⁵ Yasuda's prediction ultimately proved prescient; as the infection toll mounted it became clear that over 2,000 people with hemophilia had been infected with contaminated product, many of them at the hands of a government-owned pharmaceutical company that the Japanese hemophilia community accused of delaying the sale of international

²³ Fred Hiatt, "Tainted US Blood Blamed for AIDS' Spread in Japan."

²⁴ Fred Hiatt, "Tainted US Blood Blamed for AIDS' Spread in Japan."

²⁵ Fred Hiatt, "Tainted US Blood Blamed for AIDS' Spread in Japan."

heat-treated product until they could develop their own domestic alternative.²⁶ That revelation ensured that the story of contaminated factor reverberated outwards past the boundaries of the small hemophilia community in Japan, quickly becoming what legal historian Richard Feldman calls “one of the most volatile medical and political scandals of the postwar era.”²⁷

Yasuda’s prediction that further infections would provoke outrage also came to pass in America. By 1988, NHF realized that over 60% of America’s 20,000 people with hemophilia had contracted HIV. Cognizant of the need for clear communication on the risk of HIV and AIDS, NHF began to draw up a “White Paper” on hemophilia and HIV. The NHF White Paper openly acknowledged the extent of infection in the hemophilia community, and even broached difficult topics like safe sex that NHF had previously ignored. Despite the importance of these subjects, NHF’s national board and local state chapters collectively voted not to release the White Paper. Recalling discussions over this decision in 1988, one NHF insider said that “the chapters just got up in arms and said, ‘you can’t do this; we have people living in this community. If they’re exposed, their house could be destroyed, this will happen, they’ll be kicked out of school.’”²⁸ Despite serious pushback, NHF made some minor concessions to those who thought HIV/AIDS should be taken more seriously. The most important of these concessions was the creation of the Chapter Outreach Demonstration Project (CODP), which was designed to educate people with hemophilia who were involved in their chapters but did not receive access to treatment at a local HTC where the local hematology team could offer guidance

²⁶ Eric A. Feldman, “HIV and Blood in Japan: Transforming Private Conflict into Public Scandal” in *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*, eds. Eric Feldman and Ronald Bayer (Cary: Oxford University Press, 1999), 64.

²⁷ Feldman, “HIV and Blood in Japan,” 60.

²⁸ Susan Resnik, *Blood Saga: Hemophilia, AIDS, and the Survival of a Community, Updated Edition with a New Preface* (Berkeley: University of California Press, 1999), 156.

on AIDS.²⁹ Many community members, however, were still dissatisfied with this token gesture. Small groups of these disaffected critics had already taken advantage of NHF's annual symposium to create peer education networks that discussed topics that NHF would not, such as the risk of HIV/AIDS for the wives of men with hemophilia, or the experiences of POC with hemophilia and AIDS.³⁰ Leaders of these networks demanded that these difficult topics be given more airtime at the 1989 meeting, where tensions threatened to boil over. NHF responded by creating the Women's Outreach Network of NHF (WONN) and the Men's Advocacy Network of NHF (MANN), which respectively gave the preexisting leadership of these already-existing networks resources like access to paid social scientists and health educators.³¹

Some community members, however, gave up on NHF entirely. The lack of any clear guidance or good information about AIDS from NHF or the local HTC's in those early years had created an information vacuum, and the most disaffected people with hemophilia looked further afield than local communities to learn how to combat the virus. Bemoaning the community's poor response to HIV in 1991, one anonymous man with hemophilia told the *New York Times* that he learned of his infection in 1985 but received no helpful guidance on how to respond to it. Paraphrasing the frustrated source's remarks, the *Times* wrote that

His doctors, he said, 'never enforced any kind of fear, let alone information.' He said he was never counseled about safe sex, even though he had unprotected sexual intercourse with his girlfriend for three years, with his doctors' knowledge. His girlfriend, he said, was not infected. The man said that when he finally became ill he got no information, advice, or support from his hematologist. He said he finally learned about his options from a group of gay men.³²

²⁹ Susan Resnik, *Blood Saga*, 158.

³⁰ Susan Resnik, *Blood Saga*, 160.

³¹ Susan Resnik, *Blood Saga*, 162.

³² Gina Kolata, "Hit Hard by the AIDS Virus, Hemophiliacs Angrily Speak Out," *New York Times*, December 25, 1991, [nytimes.com/1991/12/25/us/hit-hard-by-the-aids-virus-hemophiliacs-angrily-speak-out.html](https://www.nytimes.com/1991/12/25/us/hit-hard-by-the-aids-virus-hemophiliacs-angrily-speak-out.html).

Indeed, gay men were crucial to the formation of an organized hemophilia protest movement. During the early years of contaminated factor, people with hemophilia had gone to war with gay men over the question of deferring gay plasma donors to protect the factor supply. Some of this old animosity still lingered in the early 90s, but by this time people with hemophilia who aimed to take a more aggressive posture on AIDS realized that they had much to learn from the gay community. They reached out to gay men's organizations for guidance, and came away from the experience with new tools and perspectives to confront the AIDS crisis. Michael Rosenberg, who founded the hugely influential Hemophilia/HIV Peer Association (H/HIV PA) in California, told reporters when he contracted AIDS and his brother died of it, he "ended up going to gay men for advice and support."³³ Jonathan Wadleigh, who founded the equally important Committee of Ten Thousand (COTT) around the same time, futilely attempted to convince his local NHF chapter to confront the deadly virus before attending meetings of ACT UP/Boston to learn the organizing tactics he ultimately used to launch COTT.³⁴ The organizations that these two men created became the respective faces of hemophilia activism on the East and West coasts during the 90s, and together they would launch a revolution against the established powers of hemophilia that would shake the community to its roots.

Despite the importance of these organizations within the community, these early hemophilia AIDS activists still labored in the shadow of the much larger and more visible gay rights movement for AIDS justice in the eyes of the broader public. As an anonymous man with hemophilia noted in his interview with the *Boston Globe* back in 1987, hatred for the gay community "spilled over" onto the hemophilia community through the common link of an AIDS

³³ Kolata, "Hit Hard by Virus, Hemophiliacs Angrily Speak Out."

³⁴ Susan Resnik, *Blood Saga*, 155.

diagnosis. This association presented hemophilia advocates with a dilemma: should they bolster their ranks by standing in solidarity with gay men, or work to elicit sympathy by separating themselves from them? Organizers responded to this dilemma with different tactics throughout the late 80s and early 90s, sometimes choosing to find common cause with gay men and sometimes separating from them by portraying themselves as uniquely “innocent” victims. They never totally committed to one strategy or another, instead maintaining an uneasy alliance with gay rights groups during this critical period.

On one hand, these early hemophilia activists knew that they owed the gay community a great deal for blazing a trail for AIDS activists and dealing with the brunt of a homophobic society’s hatred for AIDS victims. Wadleigh, Rosenberg, and countless other early hemophilia activists learned how to make their voices heard during the time they spent in mostly gay activist organizations and spaces, and they were in no rush to stab their fellow travelers in the back. Hemophilia activist and COTT board member Greg Haas acknowledged the debt that people with hemophilia owed gay men in the 1992 issue 1 of COTT’s newsletter *The Common Factor*, writing that “for years the gay community has led the fight, gaining expanded access to treatments, demanding study of immunomodulators, investigating alternative therapies, forcing down astronomical drug prices, making treatment and prophylaxis of opportunistic infections a priority.”³⁵ He called for people with hemophilia to involve themselves in the larger struggle for AIDS justice, arguing that

This is our fight, too! It is far past time for us to participate in the struggles that extend beyond our own particular community. That is why the COTT is an HIV advocacy organization in the hemophilia community, instead of a hemophilia organization that lists AIDS among its many concerns. COTT is actively building alliances across the entire spectrum of communities affected by AIDS... We are fighting for our health and our

³⁵ Greg Haas, “Time for Hemophiliacs to Act Up?” *Common Factor* no. 4, April 1993, 18, HFA historical papers.

lives. And the lives of our brothers and sisters in the gay community, inner cities, and everywhere else this virus replicates.³⁶

Haas's call to action is significant because it rebukes those people with hemophilia who thought of themselves as uniquely undeserving victims of AIDS. Haas believed that so long as HIV-infected people with hemophilia thought of themselves "victims," actual change would be stymied. He reminded readers that because the virus did not have a morality, concepts such as innocence/guilt were useless. Haas ended his manifesto on this point, rejecting hemophilia victimhood politics and calling for solidarity with "all of the communities affected by this damn virus."³⁷

But even as organizers like Haas called for people with hemophilia to add their voice to a common chorus of AIDS activists, other activists in the community believed that much of what they had to say would be drowned out in the crowd. They pointed out that like it or not, people with hemophilia had not contracted HIV in the same way as the gay activists who come before them. They had been infected by a greedy pharmaceutical industry that put profits ahead of human lives, and as a result they had grievances and demands that were different from those of the larger movement for AIDS justice. Michael Rosenberg articulated this view in his landmark 1992 call to arms "Causes and Effects of the Hemophilia/HIV Epidemic," writing that people with hemophilia were experiencing a "genocide" at the hands of greedy businessmen who developed unsafe therapies and a corrupt FDA that enabled them. Rosenberg asserted that the hemophilia community *was* in fact unique in its experience of AIDS, stressing the fact that "The hemophilia population is the only AIDS risk group that became HIV-infected because we

³⁶ Greg Haas, "Time for Hemophiliacs to Act Up?" 18.

³⁷ Greg Haas, "Time for Hemophiliacs to Act Up?" 18.

consumed products sold at a profit by major corporations.”³⁸ From there, he went further and threw gay men under the bus in order to draw further distinctions between people with hemophilia and other AIDS-affected groups, noting that “with the exception of persons who were transfused with contaminated blood, only our community has been brought down by AIDS precisely because we followed the advice of our doctors.”³⁹ Rosenberg’s thinly-veiled insult to the gay community demonstrated the worst instincts in hemophilia advocacy, but it also represented the fundamental dilemma facing would-be activists. If the causes of the injury that people with hemophilia experienced were unique, so too then were the remedies for that injury. If people with hemophilia wanted to receive specific and meaningful justice, then solidarity could only go so far.

The “Hemophilia Revolution” Begins

Whatever we think of their tactics and rhetoric today, COTT and H/HIV PA had no difficulty finding an audience. The hemophilia community had long been close-knit, even before the AIDS crisis. Reflecting on her time working with people with hemophilia, Sharon Barrett of the MCH remembered that “if you shared a thought with one person in the hemophilia community, it was across the country in seconds.”⁴⁰ As COTT and H/HIV PA rose to prominence, they took advantage of these long-standing networks in order to get the word out. The first issue of H/HIV’s Action Now! newsletter, for instance, was sent to a list of “500 families nationwide,” which the editors explained that they created by drawing upon “other lists

³⁸ Ronald Bayer, “Blood and AIDS in America: Science, Politics, and the Making of an Iatrogenic Catastrophe,” in *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*, eds. Eric Feldman and Ronald Bayer (Cary: Oxford University Press, 1999), 38.

³⁹ Bayer, “Blood and AIDS in America,” 38.

⁴⁰ Susan Resnik, *Blood Saga*, 141.

that were created for the purpose, explicit or implicit, of allowing persons with hemophilia to connect with each other.”⁴¹ These lists proved incredibly effective, and by the end of 1992 COTT and H/HIV PA were both major players in the world of hemophilia.

COTT and the H/HIV Peer Association arrived on the scene just as larger trends in hemophilia had begun to awaken patients to the reality of their situation. In Canada and France, for instance, federal governments had already paid out large sums of money to HIV-infected people with hemophilia and their surviving families. Rosenberg drew attention to this disparity in the first issue of *Action Now!* and questioned why NHF was not doing more to help, writing “practically every country in the industrialized world has adopted a financial assistance program for the people caught up by the H/HIV epidemic.... of course, I question why nothing has been done in the U.S.? But, even more, I want to know why our hemophilia organizations have not taken up this cause?”⁴² To make matters worse, people with hemophilia began to learn more about the industry and government decisions that produced their infection even as these international settlements piled up. The steady drip of lawsuits slowly unearthed new insights about backroom politics in the factor industry through the legal process of discovery, and certain reporters who followed the tainted factor crisis gradually found more and more whistleblowers who were willing to come forward about their time in the factor industry or the regulatory agencies. All these revelations were blasted out to the community through *Action Now!* and *The Common Factor*, which in turn only attracted more members of the community to subscribe to these newsletters. COTT, for instance, lionized Dr. Francis as a hero of the community, noting from leaked memos that even in January of 1983 Francis “warned of ‘post-factor VIII receipt of

⁴¹ Action Now! “Sorry if We Upset You,” *Action Now!* 1, issue 1, February 1992, 1, HFA historical papers.

⁴² Michael Rosenberg, “Many Nations Respond to H/HIV Needs,” *Action Now!* 1, issue 1, February 1992, 1, HFA historical papers.

AIDS,’ lamenting that ‘one-third to one-half of [persons with hemophilia] might already be exposed.’⁴³ These revelations shattered the community’s previous understanding of its infection, and almost instantly transformed AIDS discourse within the hemophilia community.

Once these stories convinced less engaged people with hemophilia that the factor companies’ explanation for their experience of AIDS was nothing more than a self-serving lie, they quickly began to rebel against the previous authorities in hemophilia care who backed that narrative. Loras Goedken, a Texas-borne person with hemophilia who had already lost seven family members to AIDS and was dying of it himself, told reporters at the Newport Daily News that “for the longest time I got up angry and went to bed angry. I was angry at gays, at drug users. Then I learned more about what the drug companies did and realized that’s who I should be angry at. All these lives gone for the sake of the bottom line.”⁴⁴ Representatives of the factor industry pushed back against these allegations, of course: reporters from the Daily News interviewed Miles Pharmaceutical’s director of corporate communications Don Hyman in the same article, dutifully publishing his response that “In a situation like this, it’s natural that the aggrieved want to look for the villain and punish him... but the villain in this case is not a company or a person. It’s the HIV virus.”⁴⁵ Unsatisfied with these excuses, however, people with hemophilia continued to sue for compensation and push for justice.

Tensions boiled over at the 1992 NHF annual meeting in Atlanta. Recalling the pandemonium of that meeting, Laurie Kelley explained that

⁴³ Corey Dubin, “SAC Revisited: or, Throw us a Compassionate Bone,” *Common Factor* no. 6, October 1993, 4, HFA historical papers.

⁴⁴ Liz Doup, “HIV-Infected Hemophiliacs: Who’s to Blame? Advocates Say Industry, Government Accountable for Epidemic of Deaths,” *Daily Press*, (Newport News, VA), October 7, 1993, <https://www-proquest-com.proxy.wm.edu/docview/342669249/FCFE7E0008B34108PQ>.

⁴⁵ Doup, “HIV-Infected Hemophiliacs.”

This was at the height of tensions between the consumer advocacy groups and pharmaceutical companies, during the HIV crisis. One group of activists even dressed as grim reapers, poured red paint on themselves to represent spilled blood, and walked among the booths at the exhibit hall, banging a drum. It was chilling, and everyone was on edge. Many pharma reps left, especially after they had received death threats. The exhibit hall became deserted.⁴⁶

Even amidst the chaos, however, community members who hoped to rehabilitate NHF worked to toe a line between the radical activists and the conservative NHF leadership. Val Bias, a MANN leader, and Glenn Pierce, a person with hemophilia who was also a physician, both ran for NHF president in 1992 on a platform of reforming the organization to meet the community's demands. Fearing that they would steal votes from one another, the two agreed that Bias would drop out so that Pierce could run on a reform platform unopposed and then appoint Bias chairman of the board once elected.⁴⁷ Writing in the aftermath of the election, Pierce told the community that "in reviewing the past year it is clear that the NHF ship needs to be turned—and not just five or ten degrees, but 45 degrees."⁴⁸ He and Val quickly set about righting the ship, implementing new community outreach programs to reach underserved populations, broaching previously undiscussed topics like safe sex, and honoring activist demands like the call to ban NHF employees from testifying against community members who sued factor companies.⁴⁹

Despite these moves, the COTT and H/HIV PA set still took issue with NHF's reforms. Reflecting back on this era, Pierce recalls that protesters "demanded our accountability, and it was very difficult to have the weight of the past fifteen years of NHF actions upon our shoulders... though we weren't the people making the decisions fifteen years ago, we were the

⁴⁶ Kelly, Laura. "NHF's 71st Bleeding Disorder Conference," *Hemablog*TM (blog), *LA Kelly Communications, Inc.*, October 7, 2019, <https://www.kelleycom.com/nhfs-71st-bleeding-disorder-conference/>.

⁴⁷ Susan Resnik, *Blood Saga*, 175.

⁴⁸ Susan Resnik, *Blood Saga*, 175.

⁴⁹ Susan Resnik, *Blood Saga*, 176.

people running the organizations, [and they saw us as] responsible for making those decisions.”⁵⁰ NHF might have begun to turn 45 degrees, but COTT and H/HIV PA called for a complete 180. Much of COTT and H/HIV PA’s grievance with NHF revolved around the national organization’s tepid response to calls for litigation and compensation. COTT and H/HIV PA favored aggressive lawsuits and petitions for government payouts, while NHF adopted a more cautious approach. NHF insisted that they opposed such calls because they would only create distinctions between AIDS victims, calling them “an ideological throwback to Elizabethan Poor Laws, with notions of deserved and undeserved populations.”⁵¹ COTT and H/HIV PA, by contrast, argued that NHF was merely continuing in its long history of carrying water for the pharmaceutical industry by blocking community demands for justice. Despite some limited collaboration and extensive listening sessions, NHF representatives left the 1992 meeting unable to find common ground with COTT and H/HIV PA.

Debates about compensation flared up again at the NHF annual meeting of 1993, where activists once again showed up in force to protest the national organization’s leadership. NHF announced that their special committee examining compensation, the SAC, had come up with a payout scheme for the factor companies. Under this scheme the factor companies would pay \$125,000 dollars for each HIV-infected person with hemophilia, with most of that money going to an NHF-managed fund that would fund community-wide programming and payout petitions for individual assistance based on perceived merit.⁵² Unsurprisingly, this proposal outraged everyone present. The factor companies refused to pay the 1.5 billion dollars that NHF’s scheme

⁵⁰ Susan Resnik, *Blood Saga*, 177.

⁵¹ David Kirp, “The Politics of Blood: Hemophilia Activism in the AIDS Crisis,” in *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*, eds. Eric Feldman and Ronald Bayer (Cary: Oxford University Press, 1999), 306.

⁵² Patricia Siplon, *AIDS and the Policy Struggle in the United States* (Washington, DC: Georgetown University Press, 2002), 59.

would entail, calling the price too steep considering the diligence they had used to protect the blood supply. The activists, on the other hand, said the amount was too low, and furthermore blamed NHF for creating a payout scheme that came with no admission of wrongdoing and funneled most of the money into NHF's own coffers rather than the hands of individual families. COTT's VP Corey Dubin wrote that NHF's compensation program was "conceptually and practically a reactive strategy designed ultimately to defend the status quo... NHF's relationship to the industry, then and now, illuminates the *why* of their response to AIDS."⁵³ H/HIV PA, for their part, came away from the meeting promising to add NHF to the list of defendants for their class action lawsuit.

COTT and H/HIV PA were set on pursuing an aggressive legal strategy in 1993 because they felt confident that courts would take their side. Although almost all the lawsuits prior to 1993 had ended in failure, COTT and H/HIV PA believed that a Boston lawyer named Eric Weinberg had discovered a new legal theory that could finally extract compensation from the factor companies. By 1993, Weinberg had unsuccessfully litigated several cases for HIV-infected people with hemophilia. During those cases, he noticed two main difficulties: blood shield laws made it incredibly difficult for people with hemophilia to hold factor companies liable for the sale of contaminated factor, and people with hemophilia had to prove that they were infected *after* the factor companies realized the dangers of HIV in order to bring charges asserting that the factor companies failed to advise patients of the risks.⁵⁴ Weinberg proposed to bypass both of those issues by bringing a lawsuit alleging that the factor companies had failed in their duty of *care* rather than their duty to warn, arguing that these corporations had the means to

⁵³ Dubin, "SAC Revisited," 4.

⁵⁴ Weinberg 51, 56.

protect the factor supply from viruses and the information to realize such protection was necessary decades earlier.⁵⁵ While developing evidence for this line of thinking he met Rosenberg, who gave Weinberg papers that documented how major factor companies turned down the Berwingwerke patent for heat-treated factor in 1978.⁵⁶ He also found a 1976 report about the risks of paid donor plasma called *Unsolved Therapeutic Problems in Hemophilia*, written in part by an FDA doctor who had since taken to testifying for the factor companies that AIDS was an unforeseeable catastrophe.⁵⁷ Armed with this evidence, Weinberg felt that he could successfully litigate a settlement on behalf of HIV-infected people with hemophilia and their families.

But who would ultimately benefit from this legal theory? This question of litigants was a contentious one; some lawyers and community members preferred to pursue individual cases on their individual merits, while others favored the idea of a class action lawsuit, and still others favored pursuing one or the other before negotiating a settlement. Lawyers who had worked separately for individual families joined forces into a Steering Committee to pursue a unified legal strategy in 1993, but these differences of opinion quickly caused rifts within the team.⁵⁸ Wary of the possibility that influential members of the Steering Committee might prefer a settlement that would undermine his cases in New Jersey, Weinberg approached COTT in 1994 and told them to form a Community Advisory Committee that could keep tab on the lawyers and prevent them from adopting a strategy that maximized fees and minimized payouts for

⁵⁵ Eric Weinberg and Donna Shaw, *Blood on Their Hands: How Greedy Companies, Inept Bureaucracy, and Bad Science Killed Thousands of Hemophiliacs* (New Brunswick, NJ: Rutgers University Press, 2017), 63.

⁵⁶ Eric Weinberg and Donna Shaw, *Blood on Their Hands*, 54.

⁵⁷ Eric Weinberg and Donna Shaw, *Blood on Their Hands*, 55.

⁵⁸ Eric Weinberg and Donna Shaw, *Blood on Their Hands*, 154.

community members.⁵⁹ These disagreements about the best legal path forwards only continued as 1994 and 1995 dragged on, culminating in a vicious flurry of suits and countersuits between the various lawyers, plaintiffs, and activists involved in the project.

Despite their new tactics, hemophilia activists experienced significant setbacks in their legal fight to extract compensation from the factor companies. Chicago judge John Grady certified that people with hemophilia had a valid class action case in his 1994 ruling on *Wadleigh v. Rhone-Poulenc Rorer, Inc.*, but the Seventh Court of Appeals overturned that ruling later that year. Writing on behalf of the Court, Judge Posner argued that a class action lawsuit presented an undue burden for the factor companies. He argued that if each case was adjudicated separately the factor companies would likely win the bulk of them, writing that “the defendants have won twelve of the first thirteen, and, if this is a representative sample, they are likely to win most of the remaining ones [individual cases] as well.”⁶⁰ If these cases were packaged together, however, Posner believed the cumulative damages would be so large that the defendants could easily be facing “\$25 billion in potential liability (conceivably more), and with it bankruptcy,” which would put them “under intense pressure to settle.”⁶¹ Citing another judge’s conclusion that “settlements induced by a small probability of an immense judgment in a class action” were essentially “blackmail lawsuits,” Posner decertified the class.⁶²

Undeterred by this setback, hemophilia activists still pushed onwards with individual lawsuits and even pressured their lawyers to appeal the ruling to the Supreme Court. The former approach proved more successful than the latter; several community members received sizable

⁵⁹ Eric Weinberg and Donna Shaw, *Blood on Their Hands*, 156.

⁶⁰ *Wadleigh v. Rhone-Poulenc Rorer, inc.* 51 F.3d 1293 (7th Cir. 1995).

⁶¹ *Wadleigh v. Rhone-Poulenc Rorer, inc.* 51 F.3d 1293 (7th Cir. 1995).

⁶² *Wadleigh v. Rhone-Poulenc Rorer, inc.* 51 F.3d 1293 (7th Cir. 1995).

settlements after the Posner ruling based on the steady drip of damning facts about the factor industry, but the Supreme Court summarily dismissed the idea of a class action suit without comment. As the lawsuits continued, VP of COTT Corey Dubin went behind the back of Wadleigh and his more stubborn peers in 1996 to negotiate a secret settlement package with the major factor corporations. Under Dubin's settlement scheme, the factor companies would offer \$100,000 dollars for each HIV-infected person with hemophilia. Taking the money would preclude them or their surviving relatives from suing the factor companies for further damages, and the factor companies would only pay out these funds if fewer than 100 families chose to opt out.⁶³ Reflecting on his negotiations with the manufacturers, Dubin told the *New York Times* that "I told him [President of Baxter International John Bacich] they were going to have to live with us as customers when all the high-powered litigators were gone... If you buy a Pinto from Ford that blows up, you can tell Ford to go to hell. But I don't have that luxury."⁶⁴ As hemophilia activists experienced disappointment after disappointment, they gradually pulled back the horizons of their ambitions.

Even as they experienced setbacks in the court system, however, people with hemophilia saw more success pressuring their congressmen and senators to investigate the tainted factor epidemic and find a legislative remedy. Their demands for action culminated in Senator Edward Kennedy, Senator Bob Graham, and Congressman Porter Goss charging Donna Shalala of DHHS with the responsibility of producing an exploratory committee that would investigate the

⁶³ Weinberg and Shaw, *Blood on Their Hands*, 218.

⁶⁴ Barry Meier, "Blood, Money and AIDS: Hemophiliacs Are Split; Liability Cases Bugged Down in Disputes," *New York Times*, June 11, 1986, <https://www.nytimes.com/1996/06/11/business/blood-money-aids-hemophiliacs-are-split-liability-cases-bugged-down-disputes.html>.

tainted factor crisis.⁶⁵ Shalala handed this task down to the IOM, commissioning them to write a retrospective report on the hemophilia HIV crisis. When the IOM task force opened for public comment in late 1994, hemophilia community members from around the country came to Washington to make their voices heard. They called for an honest account of the AIDS epidemic, compensation for its victims, and punishment for its architects. Even as factor companies sent professional representatives to the hill to explain away the gruesome side effects of their products, the community crowded the National Academy of Science's boardroom with throngs of outraged widows and dying children in order to shame their critics into silence and speak truth to power.

Jonathon Wadleigh of COTT was the first community member to testify before the committee, and his remarks set the tone for the meeting. Wadleigh called what had happened to the hemophilia community a "genocide," and told the committee that the entire community was relying on them to uncover the truth.⁶⁶ He argued that the plague that had fallen over the hemophilia community was caused by greedy factor companies and complicit government agencies rather than an unforeseeable virus, proclaiming that

The dangers of viral contamination of antihemophilic factor were well known many years prior to the AIDS epidemic yet nothing was done. Profit concerns prevailed over product safety concerns and the government agencies responsible for ensuring product safety had a long and cozy history with the blood industry, both for profit and not for profit.⁶⁷

From there, Wadleigh went on to assert that these crimes had not yet been brought to light only thanks to the concerted efforts of institutional actors who were implicated in them. He singled

⁶⁵ Correspondence from Edward Kennedy, Bob Graham, and Porter Goss to Donna Shalala, April 27, 1993, in *The Trail of AIDS in the Hemophilia Community*, ed. Dana Kuhn (unpublished manuscript, 1994), typescript, VIII-3.

⁶⁶ Committee to Study HIV Transmission Through Blood Products, "Public Meeting Held in Washington DC on September 12, 1994," transcript, National Technical Information Service, Record Locator No. PB95142345, 4-6.

⁶⁷ Committee to Study HIV Transmission Through Blood Products, "Public Meeting," 5.

out former director of NHF Alan Brownstein as one actor worthy of special blame, claiming that Brownstein told a previous congressional committee on HIV and blood safety that “there was not a problem or any outstanding questions related to the hemophilia community or the contamination of AHF.”⁶⁸ Wadleigh believed that by “covering up the culpability of NHF and doing the bidding of his long term friends in industry, Brownstein successfully convinced the Dingell committee to exclude the anti-hemophilic factor products from their investigations.”⁶⁹

Now, four years removed from these investigations, Wadleigh told the IOM committee that they had a chance to set things right. He expressed skepticism in their good faith desire to do so, however, noting that HHS’s inspector general should have handled this instead of IOM because there was “little disagreement as to the scientific facts here. The issues at hand involve ethical and policy questions related to conflict of interest in decision making.”⁷⁰ Wadleigh then went on to attack the IOM committee for not reaching out to COTT for assistance, and even questioned the very idea that factor was necessary in the first place when cryoprecipitate existed.⁷¹ He expounded on these topics at length, ignoring two separate complaints from the facilitator that he had gone over time before finally sitting down to enthusiastic applause from other community members in the audience.⁷²

Wadleigh was followed by a long litany of activists and community members, all of whom reiterated the central point that what had happened to them could have been prevented. Some of the speakers thanked the committee for their time, and offered up documents that they had acquired through their family’s litigation against factor companies; others darkly proclaimed

⁶⁸ Committee to Study HIV Transmission Through Blood Products, “Public Meeting,” 5.

⁶⁹ Committee to Study HIV Transmission Through Blood Products, “Public Meeting,” 6.

⁷⁰ Committee to Study HIV Transmission Through Blood Products, “Public Meeting,” 7.

⁷¹ Committee to Study HIV Transmission Through Blood Products, “Public Meeting,” 7-8.

⁷² Committee to Study HIV Transmission Through Blood Products, “Public Meeting,” 8.

that they had little faith in the committee itself, and named them complicit in the cover-up.

Perhaps the most memorable explanation for the tainted factor crisis came from Petra Jason, whose son with hemophilia died of AIDS 2 years before the IOM investigation. Sobbing as she spoke, Jason told the committee that “I bought that blood product, I paid for that blood product and I made my child take that product. I murdered my child but ladies and gentlemen of the commission, I did not do this alone. The drug and blood industry knew the gun was loaded and they let me shoot.”⁷³

Although the community did everything its power to make its voice heard during the IOM committee’s open sessions, the bleeding edge of hemophilia activism was simply too transgressive to be incorporated into the IOM report, which was finally published in 1995. The IOM committee was never going to echo radicals like Wadleigh, who described the community’s experiences as a “genocide of persons with hemophilia, the worst medical induced disaster in the history of mankind.”⁷⁴ Nor were they likely to accept the radical activists’ proposed remedies for that crime, which according to Corey Dubin called for nothing less than the “the immediate elimination of profit from any aspect of health care, including blood products.”⁷⁵ Instead of adopting these expansive critiques, the committee took a far more conservative approach. They infamously did not assign blame to specific actors (as discussed in the introduction to chapter 1), and often attributed goodwill to factor companies and government actors to explain away lapses in judgement that hemophilia activists described as the products of corruption and greed. If

⁷³ Committee to Study HIV Transmission Through Blood Products, “Public Meeting,” 40.

⁷⁴ Committee to Study HIV Transmission Through Blood Products, “Public Meeting,” 7.

⁷⁵ Corey Dubin, “Understanding the AIDS Crisis,” *Against the Current*, May/June 1994, <https://againstthecurrent.org/atc050/p3065/>.

members of the hemophilia community expected that the report would provide them total vindication, then they were surely disappointed by its cautious findings.

Despite these disappointments, however, the IOM report was not a total defeat for the hemophilia community. The IOM report *did* point out holistic failures in the regulation of the blood supply, and recommended sweeping reforms to prevent future catastrophes. It signed onto COTT and H/HIV PA's central critique that the hemophilia AIDS epidemic could have been prevented, for instance, writing that "heat treatment processes to prevent the transmission of hepatitis could have been developed before 1980, an advance that would have prevented many cases of AIDS in individuals with hemophilia... strong incentives to maintain the status quo, and a weak countervailing force concerned with blood product safety, combined to inhibit rapid development of heat-treated products."⁷⁶ It also called for compensation to HIV-infected people with hemophilia and their families, writing that "The federal government should consider establishing a no-fault compensation system for individuals who suffer adverse consequences from the use of blood or blood products."⁷⁷ Finally, the report recommended sweeping changes to the regulation of blood products, incorporating several suggestions from the community that eventually became durable pieces of law and regulation. COTT's request for a lookback system that periodically re-examined the risk of previously approved medicines in light of new science and technology was granted, as was their request for community input on BPAC.⁷⁸ Even if the report was not as explicit in its critiques, conclusions, and prescriptions as some activists would

⁷⁶ Committee to Study HIV Transmission Through Blood and Blood Products, *HIV and the Blood Supply: An Analysis of Crisis Decisionmaking*, Lauren B Leventon, Harold C Sox, Michael A Stoto, eds. (Washington, DC: The National Academies Press, 1995), 5.

⁷⁷ Leventon, Sox, and Stoto, *HIV and the Blood Supply*, 224.

⁷⁸ Douglas P. Starr, *Blood: An Epic History of Medicine and Commerce* (New York: Alfred A. Knopf, 1998), 349.

have preferred, it still vindicated many of the community's most important grievances and demands.

Inspired by the IOM report, in 1995 Congress took up the question of compensation. Named after the youngest child in the Ray family, who died of AIDS in 1992, the Ricky Ray Hemophilia Relief Fund Act originally offered HIV-infected people with hemophilia or their surviving families a one-time payment of \$125,000 dollars (which was later negotiated down to \$100,000). In a *Findings* preface to the bill that was cut in the final wording, its authors wrote that this compassionate payout was necessary because “the Federal Government failed to fulfill its responsibility to properly regulate the blood-products industry, and thus exposed individuals with blood clotting disorders, such as hemophilia, and their families to potential infection with a fatal disease.”⁷⁹ Ricky Ray, then, was not a wholesale vindication of the larger movement of AIDS justice, which argued that *all* people who contracted AIDS were victims of neglectful government. But because the bill's aims were so limited, it was able to attract support from legislators who would have withheld their vote for a more radical response to AIDS. When the Ricky Ray Act passed in 1998, it did so with a decisive majority of Republicans voting in favor.

Reflecting on the bill's triumph in 2016, NHF's then-CEO Val Bias explained that

The argument we made to Congress was that hemophilia is largely a male disease passed from mother to son on the X chromosome, so when these men die, they were the head of their household. They couldn't get life insurance anyways with hemophilia, so when they died their family really was financially impacted, not only then but for generations.... and in a Republican House and Congress, that sold.⁸⁰

⁷⁹ *Ricky Ray Relief Fund Act of 1995: Hearing Before the Subcommittee on Immigration and Claims*, H.R. 1023, Ricky Ray Relief Fund Act of 1995, 104th Cong. 2 (1996) (Text of the Bill).

⁸⁰ Val Bias, “Unsung Heroes: The Hemophilia Community's Response to AIDS,” National AIDS Memorial Grove, 2016, video, 9:16, <https://www.youtube.com/watch?v=oDjEpg0Vj4M>.

This heteronormative vision of a man at the head of the household providing for his wife and kids after death conspicuously excluded gay men, who also supported friends and family who would be harmed by their deaths. But by Bias's own admission this more limited appeal spoke to Republicans, and as a result the Ricky Ray Hemophilia Act sailed through Congress.

Hemophilia activists had broken ranks with their allies to win their own compensation, and they paid a political price for that decision. The AIDS Action Council, then the largest AIDS activism organization in the country, did not back the Ricky Ray Act and instead maintained a policy of neutrality.⁸¹ Other onlookers were even more contemptuous. Gay activist John Hannah sarcastically laid out the difficult dilemma facing intolerant Republicans in a local Vermont LBGT paper, writing "how can something be done about AIDS without having to admit that you've helped faggots, drug-addicts and blacks? What's a modern-day bigot to do? Answer: the Ricky Ray Hemophilia Act."⁸² Hannah then clarified his position on people with hemophilia, writing "I have nothing whatsoever against hemophiliacs. They are indeed innocent victims of AIDS. What I take strong exception to is the notion, implicit in this legislation, that other groups afflicted by AIDS are in some way 'less innocent.'"⁸³ He went on condemn hemophilia groups that supported such legislation, arguing that they had turned their backs on their allies. Like Greg Haas in the pages of COTT's first issue of Common Factor six years earlier, Hannah expected more solidarity from the hemophilia community, and rejected calls to separate people with AIDS into the categories of "deserving victims" and "undeserving victims."

⁸¹ Bayer, "Blood and AIDS in America," 48.

⁸² John Hannah, "Resurrecting the Body Politic," *Out in the Mountains: Vermont's Newspaper for Lesbians and Gay Men*, November 1997, 19, https://link.gale.com/apps/doc/CPZXSK182761283/AHSI?u=viva_wm&sid=AHSI&xid=1111d165.

⁸³ Hannah, "Resurrecting the Body Politic."

After the Dubin settlement and the Ricky Ray Hemophilia Act, the radical hemophilia justice movement gradually lost its momentum. Historian David Kirp argues that aggressive organizations like COTT and H/HIV PA rarely adopt political goals conducive to long term survival, noting that “groups like ACT-UP, which nurture themselves on a diet of high-pitched outrage, implode because they can’t sustain the requisite level of fury.”⁸⁴ This dismissive explanation may be too simplistic, however. COTT and H/HIV PA were organizations comprised of dying people with hemophilia, who knew that they only had a few years to extract justice. Even as these organizations won concessions like the Ricky Ray act or the Dubin settlement, they also lost key leaders to the deadly AIDS virus. On the “board spiritual” section of COTT’s website that lists key community leaders who have since passed away, COTT notes that they “survived the loss of nearly 60 percent of its Board of Directors during the height of the AIDS/blood epidemic during the mid 1990s.”⁸⁵ Though COTT has managed to survive in a more modest form even through these losses, H/HIV PA proved more ephemeral: Michael Rosenberg died in 1992, and the organization fell apart not long after his demise.⁸⁶ Perhaps most importantly of all, however, even the most radical people with hemophilia still relied on the people who had killed them for the clotting factor that kept them alive. As Dubin noted when he put aside his hopes for complete vindication, people with hemophilia would need to learn to live with these organizations, because living without their product was impossible. All that the community could do now was look towards the future, and guard against further abuses from the pharmaceutical industry.

⁸⁴ David Kirp, “The Politics of Blood,” 195.

⁸⁵ “Board Spiritual,” COTT, Accessed January 13th, 2021, <http://www.cott1.org/board-spiritual>.

⁸⁶ Bayer, “Blood and AIDS in America,” 38.

For a time, it seemed like very little would come from the mishandling of tainted factor in the early 80s. People with hemophilia accepted the industry's rationales for their infection for a time, genuinely believing that HIV-contaminated factor was the result of an unforeseeable tragedy rather than a preventable betrayal. Discontented activists operating on the outskirts of the community eventually pushed back on these excuses, however, and followed in the footsteps of gay men by launching a protest movement that fought for justice, recognition, and compensation. They succeeded in attaining some of their goals but fell short of others, constantly walking a tightrope between solidarity and solitude as they sought to attain their own relief without turning their backs on other AIDS-infected populations. The hemophilia community ultimately broke ranks with its comrades to win recognition and compensation from the pharmaceutical industry and the American government, putting aside the most radical planks of its political platform to achieve the possible. This decision to compromise left larger questions of justice and complicity for people with hemophilia specifically and AIDS victims more generally unanswered, however, and as a result the legacy of the tainted factor crisis is still contested to this day. In the final chapter we will examine the various meanings of the tainted factor crisis and its resolution from a modern perspective, and ponder how American medicine has or has not responded to these events.

Chapter 3

Even as the tides of hemophilia activism receded and HIV-infected people with hemophilia faded in the public consciousness, disaffected members of the hemophilia community realized that their larger demands for justice and accountability had only been half-met. Like-minded people with hemophilia began to congregate in new virtual spaces, where they discussed the still-incomplete work of hemophilia activism and worried about how society would remember their pain and loss after they were gone. Writing on one such since-deleted forum in late 1996, an anonymous and anxious person with hemophilia wondered “Hi all and what can we do?... I am speaking about the need to become seen by the mainstream population. Without resorting to violence, what can we do to once again become a discussion in the press... to be seen not as troublemakers but as people who will Not Go Away?”¹ The forum user went on to explore several possible courses of action, tentatively suggesting tactics such as “some kind of factor strike? A long-term occupation or sit-down of some sort?”² before conceding such responses were unlikely. They concluded their post on a note that was both optimistic and cautious, writing “Hang in there fellow screw-ees. We shall not be screwed again (I hope not, anyway).”³

Although this forum post is a minor footnote in the larger history of hemophilia and HIV, the questions it poses are worth considering because they perfectly illustrate the larger dilemmas and concerns facing the hemophilia community at the turn of the 21st century. Despite the best

¹ David Kirp, “The Politics of Blood: Hemophilia Activism in the AIDS Crisis,” in *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*, eds. Eric Feldman and Ronald Bayer (Cary: Oxford University Press, 1999), 311.

² David Kirp, “The Politics of Blood,” 311.

³ David Kirp, “The Politics of Blood,” 311.

efforts of hemophilia activists, who shouted out their grievances from the rooftops and rallied around ACTUP slogans like “Silence=Death,” the tainted factor crisis never made a durable impact in the American consciousness. The cursory attention that people with hemophilia *did* attract as a largely “respectable” population that was nevertheless decimated by AIDS quickly dissipated after the Ryan White and Ricky Ray acts, which the broader American public saw collectively as “justice” for their community. But even as the world lost interest in people with hemophilia, the AIDS epidemic continued to ravage their community. To make matters worse, many of the essential “blind spots” in American medicine that enabled the infection of people with hemophilia back in 1982 had still been left unaddressed in 1996. Despite all their successes, radical institutions like COTT and H/HIV PA never fully realized their aspirations to transform the entire landscape of American medicine.

Perhaps inspired by these failures, during the late 90s important leaders and organizations in the world of hemophilia began to advocate for people with bleeding disorders using more moderate rhetoric and tactics. These reformers believed that if people with hemophilia wanted to ensure that their “fellow screw-ees” would never be screwed again, they would have to transition from a short-term politics that aimed to produce outrage and spark revolution to a long-term politics that aimed to generate memory and guide reformation. They argued that whether they liked it or not, people with hemophilia could not remain in a state of permanent warfare with all the various institutions had so badly failed them so badly during the 80s. To win a seat at the table they would need to bury the hatchet, relinquishing some control over their community’s painful history to generate a new political vision for the future. People with hemophilia thus generated accounts of their community’s history *in conversation* with other stakeholders implicated in the story of tainted factor, never willing to totally cede control of the

historiography, yet also painfully aware that guarding against further abuses would require institutional cooperation.

Although these tactics have gained the hemophilia community some measure of influence and sway, they have also partially hidden the ways that the current institutional powers in the world of hemophilia resemble the bad-faith actors that came before. Many histories of hemophilia and AIDS uphold that ideological project by ending with the passage of the Ricky Ray and Ryan White Acts, using those landmark pieces of legislation to delineate the “end of an era” and labeling everything that came afterwards a “bright new future” for the community. But just as a chronological demarcation between the “golden years” and the “years of AIDS” conceals more than it reveals, so too does this false periodization obfuscate the degree of institutional continuity in the aftermath of contaminated factor products. Even if HIV-infected people with hemophilia failed to become “People Who Will Not Go Away” in the popular imagination, many of them did still live on even as other actors in the world of hemophilia moved forward from the scourge of AIDS. Their experiences still matter in ways that later leaders and institutions in the world of hemophilia refuse to acknowledge, and remembering their struggles may help us avoid a similar fate.

Memorializing the Epidemic

The first problem facing this new hemophilia community was that of remembrance. Who had the right to memorialize or historicize the era of tainted factor products in America, and which of those accounts should the community embrace moving forwards? The community’s understanding of its own infection would ultimately determine how it approached all other issues that implicated or echoed this painful history, so in many ways this issue lay at the heart of post-

contaminated factor hemophilia politics. Crucially, people with hemophilia were not the only group interested in controlling or influencing the public's understanding of the contaminated factor epidemic. Factor companies, NHF insiders, physicians, and even government regulators all were connected to this story in one way or another, and each of these groups attempted to codify their own understanding of the hemophilia community's experience with HIV into a durable historical record. While the idea of a totally "detached" historian with no personal connection to their research is of course a myth, one notable quirk of hemophilia historiography is the sheer number of researchers and authors who were also important actors in the events they worked to memorialize.

The first group to tell the story of contaminated hemophilia products were members of the community themselves, who drew upon personal experience to historicize the scourge of AIDS. Many members of the hemophilia community wrote about this history for explicitly political ends, hopeful that their accounts of the not-so-distant past could clarify the community's path forwards into the future. Elaine DePrince, for instance, wrote *Cry Bloody Murder* to educate Congresspeople who were confused by the tangled paper trail that people with hemophilia submitted as evidence of corporate malfeasance.⁴ Elaine argued that learning the hemophilia community's history could help us avoid repeating it, writing in the introduction of *Cry Bloody Murder* that "if we become informed, alert, and questioning consumers in the matter of medical treatment, perhaps we can avoid something similar happening in the future."⁵

Another distinctive feature of accounts of hemophilia and AIDS written by community members is their dual focus on the bird's eye and ground level perspectives on infection. *Dying*

⁴ Personal conversations.

⁵ Elaine DePrince, *Cry Bloody Murder: A Tale of Tainted Blood* (New York: Random House, 1997), xi.

in Vein, for instance, is a community-produced collection of photos and testimonies from HIV-positive people with hemophilia, intercut with dramatic quotes from the IOM report and detailed historical timelines that chronicled the industry's inaction in the face of AIDS. Later issues of *The Common Factor* operated in a similar method, juxtaposing the latest findings of COTT's historical investigations into HIV/AIDS against a never-ending stream of obituaries for people with hemophilia who died of AIDS-related complications. By presenting these dramatically different perspectives on AIDS side by side, people with hemophilia highlighted the causal relationship between corporate inaction and personal tragedy. They put human faces to an otherwise abstract story of big pharma run amok, forcing the reader to reckon with the tangible effects of contaminated factor.

These stories, however, represent only a small fraction of the myriad tragedies that the hemophilia community experienced because of tainted clotting factors. Many people who contracted HIV through clotting factor died before they could create a durable account of their experiences that might outlive them. Many chose to remain "in the closet," unwilling to speak up about their experiences with AIDS in such a hostile and intolerant political climate. Of that small remaining group of community members who lived long enough to document their history and chose to share their experiences with the world, only a few were lucky enough to attract enough attention that their story meaningfully permeated the historical record. I got just a small glimpse at the huge unheard body of narratives beneath the layers of official history when I visited the Hemophilia Federation of America's history room, where HFA keeps various documents and artifacts that community members have donated to them. There, among the published books and scholarly articles, was a huge mass of unexamined diaries, photo albums, and letters. As I considered this substantial body of unincorporated narratives, I was struck by how little we really

know about the various ways that people with hemophilia experienced HIV. Who were these people who produced these objects? What stories did they have to tell, and how had their exclusion from mainstream historiography warped our understanding of the trauma that people with hemophilia collectively experienced?

Unfortunately, I was unable to answer these questions. When I spoke to HFA staff about the room, they said they weren't sure if all the various families and individuals who donated materials had given any clear guidance on how they wanted their donations to be used. To avoid any breach of privacy, I confined my research of HFA's materials to sources that they were positive had been made publicly available during the AIDS crisis and its aftermath. That glimpse of those stacked-up crates, however, has stayed with me throughout this project. Even that collection of sources, as large as it might seem, is only a tiny fraction of the various perspectives on the AIDS crisis from people in the hemophilia community that have been lost to history.

This scarcity of primary sources is conspicuous in many aspects of hemophilia historiography, and looms over the entire field. Consider, for instance, all the various memos and pieces of correspondence that people with hemophilia managed to pry from the factor companies through leaks or lawsuits. Many have never been digitized, and were either disposed of by a dead community member's surviving relative or lie abandoned in dusty boxes. Thousands more documents full of pertinent information were presumably never released to the public, and lie behind closed doors if they still exist at all. Like HFA's stack of diaries or vague recollections of important community publications that were lost in a move, the absence of these sources is in of itself historically noteworthy. It serves as a reminder of just how little scholars really know about the experiences of the people who suffered during this crisis, directing our focus away from what we do know toward what we do not. Whatever other conditions of hemophilia history we can

identify, perhaps the most essential characteristic worth remembering is its all-too-common absence.

In the vacuum that a more complete account of the crisis might have filled, various other storytellers have stepped up to codify their own recollections and beliefs about the HIV epidemic into history. Factor companies, for instance, continued with the strategies they had adopted in the 90s by depicting themselves as faultless actors who had been unjustly blamed for an unforeseeable catastrophe. Their rhetorical approach was put to the test in 1995, when the IOM committee finally published its report. As discussed in both Chapters 1 and 2, the IOM report conspicuously refuses to assign culpability to individual pharmaceutical companies or regulators. It instead discusses the mismanagement of hemophilia care in only the most general terms, discussing fundamentally unsound chains of information and authority that precluded a strong and decisive response to AIDS. Even though this account of the hemophilia community's infection mostly aligned with the industry's claims of innocence, it still rankled certain blood product manufacturers. James Reilly, the President of the plasma industry's trade group ABRA, for instance, complained to the Senate in his post-IOM report remarks that "many of the IOM's findings and conclusions are without foundation and are incorrect."⁶ He applauded Secretary of Health Donna Shalala's comments about the danger of hindsight when applying blame for decisions made in a time of great uncertainty, and said ABRA "support[ed] her desire not to examine the past to assign blame, but rather to ensure a safer blood supply in the future."⁷

⁶ *H. Rept. 104-746, Protecting the Nation's Blood Supply from Infectious Agents: New Standards, Tenth Report by the Committee on Government Reform and Oversight, Together with Additional Views*, 104 Cong. 2 (1996) (testimony of James Reilly).

⁷ Reilly, testimony on *Protecting the Nation's Blood Supply*.

This “let’s move forward rather than pointing fingers!” mentality runs rampant in the industry’s rhetorical responses to almost all histories of hemophilia and AIDS that depict them as corrupt or even inept. This approach was taken up by the IOM, and has seen tepid acceptance from certain academic historians who list a story’s capacity to “heal the community” alongside strict accuracy as two competing interests worth balancing. Moving forward past a tragedy is useless, however, unless you have internalized the right lessons from it. As DePrince reminds us, people with hemophilia and people with serious illnesses more generally must become “informed, alert, and questioning consumers” if we want to avoid similar catastrophes caused by medical neglect in the future. Forgetting this history, as difficult as remembering it might be, is antithetical to that stated goal.

Outspoken activists like Durbin and DePrince are not the only ones to bemoan the reluctance of mainstream historians to confront the plight of HIV-infected people with hemophilia. They have been echoed by academics like the medical sociologists Keshavjee, Weiser, and Kleinman from the Harvard Medical School, who penned an article in 2001 criticizing the IOM committee for its failure to honestly reckon with the hemophilia HIV crisis. Keshavjee et. al. write that

By viewing the events of the 1980s as a failure of process, the IOM Report dissipated any moral culpability for the catastrophe. Instead of addressing the moral questions raised by the contamination of the blood supply, the Report converted the suffering of the hemophilia community into policy analysis and an exercise in the study of better management and regulatory oversight.⁸

⁸ Salmaan Keshavjee, Sheri Weiser, and Arthur Kleinman, “Medicine Betrayed: Hemophilia and HIV in the US,” *Social Science & Medicine* 53, no. 8 (2001): 1089. doi:10.1016/s0277-9536(00)00403-2.

Because of this institutional failure to historicize the crisis, the trio writes, much of the hemophilia community's pain has largely been excluded from the official record. They draw parallels between the hemophilia's subaltern memory of collective loss and other recollections of similarly traumatic catastrophes, writing that the hemophilia community's understanding of its own infection echoes that of "Holocaust survivors, atomic bomb survivors, Vietnam war veterans, refugees from political violence and sufferers of natural disasters."⁹ Tying all these groups together is their shared experiences with traumatic events that both inherently resist historization and attract critics that would rather see them forgotten, creating a layer of unspoken recollection that resides below official history. Citing the work of literary critic and Holocaust scholar Lawrence Langer, Keshavjee and his peers call this unspoken understanding of the hemophilia community's loss a form of "deep memory."¹⁰

Factor companies were not the only recounters of hemophilia history who felt ill at ease with attempts to clarify these questions of responsibility and complicity. Dr. Evatt of the CDC learned that lesson in 2006, when he wrote a retrospective account of the hemophilia community's experiences with AIDS in *The Journal of Thrombosis and Haemostasis*. Evatt was very critical of the factor companies, the FDA, and the medical experts at MASAC who urged NHF to stay the course. He argued that an entire generation of people with hemophilia could have been saved if these actors had heeded the CDC's warnings quicker or devoted more energy to developing safe products before HIV/AIDS arrived onto the scene.¹¹ Unsurprisingly, Evatt's conclusions provoked controversy. His most vocal critic was probably Dr. Aledort, who played a

⁹ Keshavjee, Weiser, and Kleinman, "Medicine Betrayed," 1090.

¹⁰ Keshavjee, Weiser, and Kleinman, "Medicine Betrayed," 1090.

¹¹ B.L. Evatt, "The Tragic History of AIDS in the Hemophilia Population, 1982–1984," *Journal of Thrombosis and Haemostasis* 4, no. 11 (2006): 2298, doi:10.1111/j.1538-7836.2006.02213.x.

critical role in convincing NHF's MASAC counsel to adopt a conservative response to AIDS in the 80s. In a 2007 response to Evatt's article that appeared in the same journal, Aledort wrote that

Almost 25 years after the first hemophilia patient developed clinical manifestations of HIV, a paper has been written vilifying treaters, the blood-manufacturing industry and the blood-banking industry. At a time when patients with hemophilia are beginning to move forward on this terrible issue, this self-serving, inaccurate paper demands documentation and/or its correction.¹²

Like the factor companies, Aledort uses bromides about the virtues of "moving forward" to attack historical attempts to uncover the past. He makes this point even more explicit toward the end of his paper, concluding that "One can never argue about the virtue of revisiting history, but this is a prime example of rewriting history. Now is the time of healing, not finger-pointing."¹³ Evatt, for his part, remained unconvinced by these arguments. He wrote a cursory response to Aledort in the very same issue of the journal, suggesting in an understated academic voice that "the historical facts and concepts that Aledort implies were grievous omissions by the author are in fact Aledort's redaction of facts and/or concepts clearly presented and well referenced in the article. The reader is urged to refer to the article and its references if additional clarity is needed."¹⁴

It's easy to recall Aledort's role in this history of hemophilia and HIV and consider how that role might shape his recollection of this history, but it's equally important that we remember Evatt's role in these events and consider its effects on *his* recollections as well. Evatt, like

¹² L.M. Aledort, "HIV and Hemophilia," *Journal of Thrombosis and Haemostasis* 5, no. 3 (2007): 607, doi:10.1111/j.1538-7836.2007.02371.x.

¹³ Aledort, "HIV and Hemophilia," 608.

¹⁴ B.L. Evatt, "HIV and Hemophilia," *Journal of Thrombosis and Haemostasis* 5, no. 3 (2007): 608. doi:10.1111/j.1538-7836.2007.02398.x.

Aledort, wielded considerable institutional power at a time where institutions sat idly by as people with hemophilia used contaminated factor in complete ignorance. The historical record generally supports Evatt's claim that he and his colleagues at the CDC were consistent and diligent advocates for the hemophilia community long before their peers recognized the risks of HIV, but the fact that Evatt is an important author in the primary *and* secondary literature of that historical record should give us pause.

In this, of course, Evatt is not alone. Many seminal histories of the hemophilia AIDS epidemic were written by authors who played important roles in that history. Susan Resnik's *Blood Saga*, for instance, has been an invaluable resource for me throughout this project. Yet Resnik is an ex-NHF employee, albeit one who left the organization a few years before the emergence of HIV in the blood supply. Knowledge of Resnik's time at NHF informs our understanding of certain historical conclusions she comes to, such as her decision to clearly separate the "golden years" of hemophilia from the "years of AIDS" and her reticence to examine the community belief that NHF's reliance on the factor industry made them ineffectual advocates. As a result of Resnik's connections, some members of the community have rejected her account of this history entirely. One anonymous commenter on Amazon, for instance, writes "Shame on the author for participating in the widespread 'sweeping under the carpet'" before accusing Resnik's account of glossing over the way that "National Hemophilia Foundation sold their soul by taking big payments from these companies."¹⁵ This user who wrote this comment problematizes Resnik's work by invoking what Langer would call "deep memory" of the contaminated factor crisis, calling attention to the ways that mainstream historiography has

¹⁵ Butterfly8888, January 18, 2010, customer review on Amazon storefront, "Blood Saga: Hemophilia, AIDS, and the Survival of a Community, Updated Edition with a New Preface," https://www.amazon.com/gp/customer-reviews/R1SILPPQHPOZHK/ref=cm_cr_dp_d_rvw_ttl?ie=UTF8&ASIN=0520211952.

excluded the hemophilia community's understanding of its own infection. By the same token, however, a certain belief is not true simply because members of the hemophilia community believe it. Conspiracy theories and unsupported beliefs about this history still abound in the hemophilia community even to this day, and there is much to be done when it comes to untangling fact from fiction in both official and unofficial accounts of the contaminated factor crisis.

These problem of authorship in hemophilia/AIDS remembrance extend beyond scholarly history and personal autobiography, and will continue to crop up in other issues examined in this chapter. Key individuals and institutions in the world of hemophilia have tried to memorialize the community's history in a range of mediums to serve a variety of ends, and each of these attempts has spawned its own unique discourse. The question of a physical hemophilia AIDS memorial, for instance, has been the subject of considerable controversy over the last three decades. Even as early as 1999, COTT had begun to call for a permanent memorial dedicated to people with hemophilia who had died of AIDS. Despite widespread enthusiasm, people with hemophilia struggled to find space and money to erect such a monument. Prospects for a permanent memorial seemed dim until 2016, when NHF announced that they had negotiated an agreement for a small memorial for people with hemophilia inside the AIDS Memorial Grove.

Although most members of the community welcomed the news, NHF and the Grove's specific vision for the memorial sparked two small controversies. The first had to do with NHF's proposed dedication of the memorial: they had initially planned for the monument's plaque to mention their own role in securing the site, which angered community members who believed that NHF had failed them in the 80s. NHF ultimately agreed to determine the plaque's inscription through a community vote, which decisively shot down any idea of using the memorial to lionize

the organization.¹⁶ The second (far uglier) controversy came from people with hemophilia who objected to the location of the site itself. Falling back on claims of “special victim” status and base homophobia, they argued that people with hemophilia were fundamentally different than the other victims of AIDS who were memorialized in the grove. NHF and the Grove made no concessions to this second group, thus implicitly rebuking those members of the hemophilia community who wanted to carry on this old “hemo-homo war” decades after the blood supply had been secured.

Contested Legacies of AIDS in the Hemophilia Community

Indeed, the still-ongoing relationship between gay men and people with hemophilia is perhaps the best place to begin as we transition from a discussion of hemophilia memory to an exploration of how that memory has shaped more recent politics. People with hemophilia and gay men have historicized the role of people with hemophilia in AIDS advocacy in very different ways, and these divergent theories about hemophilia politics have informed more recent moments where the interests of these groups intersect or diverge. People with hemophilia, for their part, mostly view themselves as a relatively innocent party. If they did not actually stand in solidarity with gay men, the thinking goes, then they at least refused to be actively complicit in homophobic rhetoric that might have won them friends on the right. One NHF employee who worked at the organization during the 90s offered this view to Susan Resnik during interviews she conducted for *Blood Saga*, explaining that “We were then approached by . . . right-wing groups to engage the National Hemophilia Foundation in this war against ‘sin.’ . . . I’m really

¹⁶ “Choose the Inscription on the Hemophilia Memorial,” NHF, Accessed March 22, 2021, <https://www.hemophilia.org/news/choose-the-inscription-on-the-hemophilia-memorial>.

proud of the role of the hemophilia community in resisting these demagogues.”¹⁷ Gay men, on the other hand, often had far less rosy memories of the hemophilia community’s involvement in AIDS politics. Gay historian Jeffery Bennett argues that the hemophilia community explicitly threw gay men under the bus in his book *Banning Queer Blood*, concluding that “hemophiliac organizations in the past frequently adopted a language that was explicitly homophobic in order to advance their goals. Such organizing was so successful that Congress passed the Ricky Ray Act.”¹⁸ He also argues that people with hemophilia continue to prop up a ban on gay blood donors both implicitly and explicitly, concluding that the community still occupies a central space in “discourses that isolate those who were “innocent victims” from those who ‘deserved’ AIDS.”¹⁹

Both recollections of hemophilia AIDS politics have been invoked in recent memory during political battles over the FDA’s policy of gay blood donor exclusion. Starting in 2006, the FDA began to revisit the lifetime ban on gay men donating blood every two years. Each of these biannual reviews provoked a flurry of media inquiry about the ban, which in turn brought people with hemophilia and gay men back into discourse about the ban and its history. In 2008, for instance, NHF’s CEO Val Bias told reporters at a Chicago-based news syndicate that he believed the policy should stand unchanged. Invoking that age-old paradigm that pitted the lives of people with hemophilia against the rights of gay men to live without stigma and ignoring the decades’ worth of science that had changed that calculation, Bias asked “why fix anything that is working? It’s just really not worth it...Everyone has rights. But I don’t think that anyone has the

¹⁷ Susan Resnik, *Blood Saga: Hemophilia, AIDS, and the Survival of a Community, Updated Edition with a New Preface* (Berkeley: University of California Press, 1999), 128.

¹⁸ Jeffery A. Bennett, *Banning Queer Blood: Rhetorics of Citizenship, Contagion, and Resistance* (Tuscaloosa: University of Alabama Press, 2009), 74.

¹⁹ Bennett, *Banning Queer Blood*, 56.

right to put someone else at risk.”²⁰ Two years later, at the height of the ban’s 2010 coverage, Gay Men’s Health Crisis released a report on the policy titled “A Drive for Change: Reforming U.S. Blood Donation Policies” that called for its immediate end. While speaking to editors at the HIV-focused magazine *POZ*, GMHC director and report editor Dr. Sean Cahill suggested that “Many policies adopted toward HIV a quarter century ago were based on fear, prejudice, homophobia and ideology—not science and compassion.”²¹ Although Cahill leaves it to the reader to decide which exact policies he is referring to, the FDA infamously codified its previously-provisionary 1983 ban on MSM men donating blood into permanent policy in 1986. HIV tests were still unreliable and new at that time, and gay men made up the largest at-risk group for HIV that the CDC had identified. By arguing that the ban had always been based on “fear, prejudice, homophobia and ideology,” Cahill suggested that the people with hemophilia who vociferously argued for the ban during that uncertain time were guilty of all the above.

Although important organizations like GHMC and NHF fought over the blood ban by invoking these diametrically opposed visions of hemophilia politics, they also tactically revised, softened, or even reconciled these visions of the hemophilia community’s past in attempts to find common ground. In 2008, for instance, GHMC and NHF co-authored a letter with a variety of other gay and hemophilia interest groups to “clarify a recently encountered misperception” that there was a “disconnect between the positions of leading gay rights and hemophilia representatives.”²² The authors went on to explain that their “communities have more in common

²⁰ Lisa M. Krieger, “FDA’s Blood-Donation Ban: Does it Save Or Risk Lives?,” *McClatchy - Tribune News Service*, Mar 03, 2008, <https://proxy.wm.edu/login?url=https://www-proquest-com.proxy.wm.edu/wire-feeds/fdas-blood-donation-ban-does-save-risk-lives/docview/456847611/se-2?accountid=15053>.

²¹ James Wortman, “Ending the Gay Blood Donation Ban,” *POZ*, March 3, 2010, <https://www.poz.com/article/gmhc-gay-blood-hiv-report-18084-6449>.

²² AIDS Action Council et. al., “Joint Statement on Addressing the MSM Blood Ban by Groups Representing People Living with Hemophilia, Gay Men and People Living with HIV/AIDS,” June 9, 2010, <https://www.hemophiliafed.org/uploads/2010/06/GMHC-Hemophilia-Jt-Letter-Final.pdf>.

than current discourse reflects,” such as a common history in which they “worked toward shared goals, including caring for people living with HIV and preventing the virus’s spread.”²³ Importantly, the letter does not engage in total historical revisionism by suggesting that gay men and people with hemophilia always or even often worked *together* toward those goals, merely that the goals themselves were shared. It ends with a tepid affirmation that both communities support revising the ban in accordance with new science, conveniently leaving out the larger point that the organizations representing these populations did not actually agree on what a science-based approach entailed. This letter, after all, was written contemporaneously with Cahill’s suggestion that the science never called for a ban, and two years before Bias’s suggestion that the science *still* called for a ban. Over time, however, this hybrid version of hemophilia history that emphasized the common priorities and causes that people with hemophilia shared with gay men slowly facilitated a compromise. In 2012, Val Bias told reporters for the Washington Times that lifting the ban still called for more research, but also said he was “encouraged” by recent data and would “continue to work with all interested parties” to create a policy based on new science.²⁴ When the FDA finally revised the ban in 2014, they did so with NHF’s blessing.

Although this limited treatment of hemophilia memory in the blood ban debate reduces the total of possible viewpoints to two diametrically opposed options that slowly converged, it’s important to remember that there was a considerable diversity of perspectives not represented by this dominant framework. COTT, for instance, spoke out against the blood ban long before its eventual overturn. In a private letter to Dr. Jay Epstein at the FDA’s Office of Blood Research

²³ AIDS Council et. al., “Joint Statement.”

²⁴ Cheryl Wetzstein, “Study could end ban on gay men donating blood,” *Washington Times*, May 16, 2012, <https://www.washingtontimes.com/news/2012/may/16/study-could-end-ban-on-gay-men-donating-blood/>.

written in 1997, COTT's Medical Committee condemned the MSM policy for its "existing bias regarding gay and bisexual men" before demanding a policy based on "behaviors associated the transmission of virus rather than on specific individuals or communities."²⁵ By the same token, gay rights groups and activists usually acknowledged that a ban was more defensible in 1983 than it was in 2010. Some went even further by alleging that some limited ban might *still* be necessary, such as gay legal scholar Adam Pulver. In 2008, Pulver wrote a relatively vigorous defense of the blood ban titled "Gay Blood Revisionism." Like the title suggests, Pulver argued that younger college-based LGBT activists that pushed for a wholesale lifting of the ban suffered from a "lack of memory of the AIDS crisis."²⁶ Although he did not offer any answers to these questions, Pulver also argued that any debate about the ban hinged on determinations about "what is an acceptable risk, and what increase in risk is ethically justified in order to reduce feelings of stigma."²⁷ COTT's relatively quick rejection of the ban and Pulver's relatively slow rejection of it demonstrate that neither people with hemophilia nor gay men adopted uniform positions about how hemophilia history should inform policy makers' attitudes on the blood ban.

Invocations of the hemophilia community's experience with AIDS have also appeared in debates over the extent and nature of the relationships that various stakeholders in the world of hemophilia should form with one another. These stakeholders are too numerous for all their interconnected relationships with one another to be discussed in detail, but they include doctors, industry/industry representatives, community organizations, regulatory agencies, and individual patients. Running through all these relationships that comprise the post-AIDS world of

²⁵ Correspondence from COTT Medical Committee to Dr. Jay Epstein, June 19, 1997, HFA historical papers.

²⁶ Adam Pulver, "Gay Blood Revisionism: A Critical Analysis of Advocacy and the 'gay Blood Ban,'" *Law & Sexuality* 17 (2008): 109, doi: 10.2139/ssrn.1316112.

²⁷ Pulver, *Gay Blood Revisionism*, 128.

hemophilia is an awareness that each of these stakeholders possesses their own unique set of interests and incentives. The optimistic view of hemophilia care, which situated all these groups' interests in easy alignment with one another, has been irreparably ruptured by the trauma of AIDS. Stakeholders can form tactical alliances with one group or another or even proclaim their universally benevolent intentions by either reframing or eliding over hemophilia history to suit their purposes, but the community's "deep memory" of the AIDS crisis has thus far prevented people with hemophilia from totally forgetting how many of these stakeholders put their personal interests over the community's collective safety when HIV entered the blood supply.

Medical providers were one group to lose considerable prestige from this re-evaluation. At the height of hemophilia AIDS activism, certain physicians who urged patients to "stay the course" on clotting factor were reviled. Aledort, for instance, was called the "Joseph Mengele" of the "hemophilia Holocaust" by certain activists who blamed him for NHF's inaction. More common than these specific attacks, however, was a general sense that the entire medical profession had failed people with hemophilia. Unlike some other radical community beliefs that challenged established centers of power, this institutional distrust of the medical profession has seen considerable attention in secondary literature about the contaminated factor crisis.

Keshavjee, Weiser, and Kleinman cite the testimony of several people with hemophilia at the IOM committee hearings to demonstrate this distrust in a section of their paper titled *Physicians: care givers or care sellers?*, concluding with Joey Lawson's remark that "Never again will I trust the medical profession. How can I?" to drive their point home.²⁸

²⁸ Keshavjee, Weiser, and Kleinman, "Medicine Betrayed," 1084.

Potential conflicts of interest still abound for professional caregivers working in hemophilia. Federal funding for the Hemophilia Treatment Center (HTC) program has stayed stagnant over the past few decades, even as inflation and rising medical costs have made running an HTC program increasingly more expensive. Many HTCs have dealt with this problem by joining the 340B Drug Pricing Program, meeting federal standards set out in the Public Health Services Act of 1992 that allow a clinic to purchase and sell drugs at a discounted rate. Qualifying for 340B status essentially lets HTCs function as specialty pharmacies, which in turn lets them provide essential services to the community. According to one survey of HTCs conducted in 2018, “the majority of centers rely on 340B program income to fund > 90% of the staff time of nurses, social workers and physical therapists.”²⁹ Although 340B status is certainly lucrative for HTCs, it also creates opportunities for a conflict of interest. Many HTCs that act as specialty pharmacies will not secure deals with all the various factor manufacturers, and rare HTCs that do supply most or even all the existing factor products will not receive equally lucrative deals from the various manufacturers. HTC hematologists can also raise money by using their clinics as nexuses to enlist patients into industry drug trials, monetizing their unusual relationship with patients to populate these studies with otherwise difficult-to-find people with hemophilia.

Taken together, these dual incentives undermine patient trust that their HTC’s recommendations are motivated by medical concerns rather than financial ones. In May 2009, Laurie Kelly (a “hemophilia mom” and community advocate) published an issue of her “Parent

²⁹ Rebecca A Malouin et. al., “Impact of the 340B Pharmacy Program on Services and Supports for Persons Served by Hemophilia Treatment Centers in the United States,” *Maternal and Child Health Journal* 22, no. 9 (2018): 1243, doi:10.1007/s10995-018-2545-7.

Empowerment Newsletter” that was largely dedicated to navigating these issues with HTC’s. Summarizing her experiences with HTC’s who tried to enlist her son into their 340B, another hemophilia mother named Jane explained that “whether it’s a legitimate concern or not, it makes you think that money — and not necessarily patient care — is their motivating force. It undermines my confidence in the treatment we’re receiving.”³⁰ Whether Jane made the parallel consciously or not, her remarks echo past critiques from hemophilia activists who alleged that their doctors prioritized industry money over patient safety.

Another relationship that can be examined through the prism of hemophilia history is the relationship between patient advocacy groups and the pharmaceutical industry. At the nadir of NHF’s guardianship over the community’s interests in the early 80s, NHF received around 20% of its operational budget from pharmaceutical corporations.³¹ When news about the full extent of this funding stream went public in the aftermath of the tainted factor crisis, grassroots hemophilia activists directly linked NHF’s funding with its conservative response to AIDS. Corey Dubin, for instance, wrote in 1994 that the “close relationship between the drug companies the NHF had tragic consequences...NHF continued to advise its members to use the blood products, advice we now know contributed to 10,000 HIV infections.”³² Although NHF did institute new safeguards like bolstered conflict of interest policies and additional preconditions that had to be met before accepting a grant, they never totally cut the tap.

When NHF refused to cut ties with industry, hemophilia activists responded by creating alternative organizations. Michael Rosenberg, for instance, wrote in 1991 that “We— the

³⁰ Kevin Correa, “Patient and Physician: Communication and Conflict in a New Hemophilia Era,” *Parent Empowerment Network*, May 2009, <https://www.kelleycom.com/wp-content/uploads/2018/06/may2009pen.pdf>.

³¹ Susan Resnik, *Blood Saga*, 196.

³² Corey Dubin, “Understanding the AIDS Crisis,” *Against the Current*, May/June 2009, <https://againstthecurrent.org/atc050/p3065/>.

alienated— do not identify with the hemophilia institutions. After all the debacle of the 80s, we do not need an organization that cozies up to the corporate factor makers; we do not need an organization that can be bought off cheaply with small grants and PR gimmicks.”³³ COTT realized Rosenberg’s vision in 1994, creating a split-away organization that they claimed would advocate for the hemophilia community’s holistic needs without industry money. COTT leaders called this patient-focused alternative the Hemophilia Federation of America (HFA), and presented it as an authentically grassroots alternative to NHF. Only 6 years later, however, HFA caved to the financial realities of running an active patient advocacy org without industry support and formally reversed its policy of financial independence from pharmaceutical corporations. Although they too implemented extensive conflict of interest and transparency bylaws to guide these donations, they nevertheless departed from one of the major founding precepts of the original HFA vision. In their statement explaining the move, HFA wrote that

The Hemophilia Federation of America believes that, unlike the actions of the past, industry is now more committed to ensuring product safety. The Hemophilia Federation of America believes furthermore that mandatory government regulations, commissions and other forms of oversight have greatly reduced the chance of history repeating itself, especially since these measures recognize and include meaningful community input.³⁴

Rather than a commitment to “never again” based on active vigilance against further catastrophes, HFA’s version of “never again” comes close to denying that such vigilance is even necessary in a modern world of hemophilia. No major patient organization has advocated for

³³ Ronald Bayer, “Blood and AIDS in America: Science, Politics, and the Making of an Iatrogenic Catastrophe,” in *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*, eds. Eric Feldman and Ronald Bayer (Cary: Oxford University Press, 1999), 40.

³⁴ “Our Vision / Mission,” HFA, Accessed April 11, 2021, <https://www.hemophiliafed.org/home/our-role-and-programs/what-is-hfa/our-mission-vision/>.

people with hemophilia without accepting money from the corporations who produce hemophilia therapies since this decision in 2000.

In many ways, the hemophilia community does share common interests with the pharmaceutical industry. Pharmaceutical companies that produce factor only care that their product is bought at a steep cost, with very little preference toward who ultimately pays for it except insofar as the payer's identity impacts sales. Hemophilia advocacy organizations, on the other hand, only care that patients can afford factor products, with very little preference on the cost that insurers ultimately pay for those drugs except insofar as that price impacts patient access. Hemophilia advocacy organizations and pharmaceutical companies thus work together in legislatures all around the country, advocating for state and federal governments to compel insurance companies who balk at the sky-high prices of clotting factors to offer robust, affordable plans that cover clotting factor for people with hemophilia. In 2016, for instance, researchers noted that the factor company then known as Baxter had given out almost 2 million dollars in advocacy grants to NHF and HFA chapters since 2003, often with stipulations that the groups would direct the money towards causes like conducting "grassroots advocacy campaigns, directed at key decision makers, in an effort to preserve quality of care."³⁵ Lest you feel too sad for the poor insurers, however, know that they are also well represented in the legislative process. Despite new protections for people with chronic health conditions such as the ACA, insurers and end payers are still hard at work trying to find ways to avoid paying for expensive specialty therapies like clotting factor.

³⁵ Philip Kucab, Katelyn Dow Stepanyan, and Adriane Fugh-Berman, "Direct-to-Consumer Marketing to People with Hemophilia," *PLOS Medicine* 13, no. 6 (2016): 5, doi: 10.1371/journal.pmed.1001996.

And make no mistake, modern clotting factors *are* expensive. After the debacle of contaminated factor products, the pharmaceutical industry responded to patient demands for a safer product by switching to synthetically derived factor molecules. These new products, known as “recombinant” clotting factors, first came to market in 1992 and have since become the de-facto norm for people with hemophilia.³⁶ Although recombinants have so far been incredibly safe therapies, they have also been incredibly expensive. In 2018, reporters from KHN wrote an article on high drug prices that cited data from PBM Express Scripts to estimate that the average adult male with complication-free hemophilia in America goes through about \$270,000 worth of factor in a year.³⁷ As hematologist Dr. Croteau explains it, “Many of these products were licensed in the early 1990s or 2000s, and while there are certainly new variations, especially in the FVIII market, there is not huge variability in characteristics...yet, they keep getting more expensive.”³⁸ Because a relatively low number of sellers have consolidated majority control over the market, the factor industry has been described as an “oligopoly” and “fundamentally non-competitive” in recent scholarly literature.³⁹ Even though the scourge of HIV has been eliminated from the blood supply, in other words, the market’s underlying predation on and commodification of people with hemophilia has by no means abated.

Despite these impositions, the same total reliance on the pharmaceutical industry that precluded an all-out legal war in 1992 and a factor strike in 1996 has also prevented people with hemophilia from aggressively pushing back against the industry’s prices. What’s more, many

³⁶ Kamilla Swiech, Virginia Picanco-Castro, and Dimas Tadeu Covas, “Production of Recombinant Coagulation Factors: Are Humans the Best Host Cells?” *Bioengineered* 8, no. 5 (2017): 463, doi: 10.1080/21655979.2017.1279767.

³⁷ Jenny Gold, “Of ‘Miracles’ and Money: Why Hemophilia Drugs Are So Expensive,” KHN, March 8, 2018, <https://khn.org/news/of-miracles-and-money-why-hemophilia-drugs-are-so-expensive/>.

³⁸ Leah Lawrence, “The High Price of Hemophilia,” ASH Clinical News, February 1, 2020, <https://www.ashclinicalnews.org/spotlight/feature-articles/high-price-hemophilia/>.

³⁹ Kucab, Stepanyan, and Fugh-Berman, “Direct-to-Consumer Marketing to People with Hemophilia,” 6.

people with hemophilia and organizations that advocated on their behalf were so relieved to see safer products that they accepted the higher price tag that came with them. One collaboratively authored paper on factor costs from 2002 commented that pharmaceutical companies relied on the community's fears to set their own prices, noting that the promises of recombinant products appealed to "patients and doctors who, still in the shadow of viral epidemics spread through clotting factor, desire to have safer and purer products."⁴⁰

My brother was born right as the first recombinant products were created, and spent the first few years of his life on human product. When a recombinant alternative finally became available to people his age, the local HTC hematologist was adamant that our family should stay on human clotting factor. He said that the price tags for all the recombinant alternatives were exorbitant, and (correctly) pointed out that the modern-day blood products were far better screened, cleaned, and regulated than their primitive ancestors. Ultimately, my parents' decision was made for them by an outbreak of vCJD that doctors feared might permeate the blood supply. My family, like thousands of others who were also slow to adopt recombinants, responded to the news by instantly abandoning human factor in fear that history might repeat itself.

Despite high costs and past betrayals, patient advocacy institutions in the hemophilia community have put aside their differences with the factor companies to pursue common goals. Perhaps *because* of their high costs and past betrayals, factor companies have been unusually eager to forge close relationships with patient advocacy organizations. Although NHF does not publish full breakdowns of the donations they receive, publicly available information does paint a stark picture of the industry's role in their continued financial stability. NHF's current

⁴⁰ Rogoff et. al., "The Upward Spiral of Drug Costs: A Time Series Analysis of Drugs Used in the Treatment of Hemophilia," *Journal of Thrombosis and Haemostasis* 88, no. 4 (2002): 551, PMID: 12362223.

operating budget has almost tripled from its 2002 appraisal at ~7 million dollars, with most of that growth coming from contributions.⁴¹ Donation information is not available for all the various factor companies, but Pfizer reported donating \$1,115,000 to NHF's central office and various decentralized chapters in 2015.⁴² Crucially, most of this money is not oriented towards advocacy. During my own time in the community, I have seen factor companies sponsor chapter summer camps, college scholarships, financial hardship support funds, annual symposiums, "healthy living" excursions, and professional development workshops for young adults. They also fill community organizations' pocketbooks by buying advertisements in magazines like NHF's Hemaware, which researchers have found consistently violate or bend FDA regulations on honest advertising by exaggerating the benefits of new products and downplaying the risks.⁴³ All told, these various fundraising streams ensure that the hemophilia community is constantly awash with industry cash.

The fact that the very organizations that would ideally critique these relationships are in fact participating them has dampened the community's response, but many people with hemophilia are aware of these fundamental conflicts. Several of them whom I've met during my time in the community have characterized these funds as "blood money," and questioned how industry dollars influence the policy goals of advocacy organizations. Others have drawn parallels between industry's current ties to the community and the connections it forged before the HIV crisis, arguing that these methods of influence peddling undermined the community's

⁴¹ "Charity Navigator: Historical Information for National Hemophilia Foundation," Accessed April 16, 2021, <https://www.charitynavigator.org/index.cfm?bay=search.history.detail&orgid=5019>.

⁴² Kucab, Stepanyan, and Fugh-Berman, "Direct-to-Consumer Marketing to People with Hemophilia," 5.

⁴³ G.A. Abel et. al., "Direct-to-consumer Advertising for Bleeding Disorders: A Content Analysis and Expert Evaluation of Advertising Claims," *Journal of Thrombosis and Haemostasis* 6, no. 10 (2008): 1680-1684, doi: 10.1111/j.1538-7836.2008.03083.x.

capacity for independent advocacy in the face of AIDS. Although she does not make this connection explicitly, Susan Resnik's description of historical tactics that factor companies used to curry favor with NHF in the 70s does suggest certain striking parallels. Resnik quotes one Hyland Laboratories sales representative who thought that this feature of the industry's involvement in the community was particularly interesting, recalling that "I find all of the manufacturers and representatives of the companies involved in many, many ways. And there is a range of things: participating in summer camps, participating in . . . workshops that the families attend, and trying to help the nurse coordinators."⁴⁴ HFA and NHF are certainly far more independent and autonomous than the advocacy organizations of yesteryear, but the fact that current day-programs they offer echo this description so uncannily should give us pause.

Although some of these more egregious programs already stretch the boundaries of professional propriety past the breaking point, many manufacturers working in hemophilia care have gone even farther by wooing customers through channels that bypass advocacy organizations all together. Pharmaceutical sales reps, for instance, have historically volunteered at the camps that their employers financed to form early connections with prospective customers. Sales reps can then build upon these relationships that they forge during community events with a variety of tactics, including paid meals out with their "friends," professional development trainings and scholarships for people with hemophilia, and even offers of paid consulting/speaking opportunities, all in the hopes that the patient might eventually agree to switch brands.⁴⁵ As a patient who has been on the receiving end of all these tactics and more, I can personally attest to their ubiquity in the hemophilia community today. In their paper on these strategies, Philip

⁴⁴ Susan Resnik, *Blood Saga*, 98.

⁴⁵ Kucab, Stepanyan, and Fugh-Berman, "Direct-to-Consumer Marketing to People with Hemophilia," 3.

Kucab (a person with hemophilia) and his co-authors convincingly make a case that “Factor manufacturers target many individuals with hemophilia using strategies similar to those used to market drugs to physicians.”⁴⁶ In a disease state where convincing three patients to switch products could represent over a million dollars’ worth of annual revenue, the primary rationale for these aggressive sales tactics is obvious. Less obvious, however, is the secondary effect that these marketing schemes create by obscuring the historical tensions between people with hemophilia and the corporations that profit from them. They suggest some common confluence of interests where none exists, and thus contribute to a broader crisis of amnesia about the pharmaceutical industry’s role in the HIV crisis.

To make these problems even more confusing, many of the sales representatives who work in this business of patient recruitment are community members themselves. As NHF’s vice president of public policy and stakeholder relations Michelle Rice explained to the *New York Times* in 2016, “There are a lot more patients that work in industry now than ever before.”⁴⁷ It’s hard to begrudge people with hemophilia for making that decision. Many of them took these positions for their insurance, since finding plans that would cover someone with hemophilia and HIV was almost impossible before the ACA. Organizations in the hemophilia community have struggled to find approaches that recognize these individuals as both community members *and* industry representatives, with varying degrees of success. My local NHF chapter, for instance, banned certain community members from attending events geared toward new parents and created best practices for withholding certain information from board members who work for

⁴⁶ Kucab, Stepanyan, and Fugh-Berman, “Direct-to-Consumer Marketing to People with Hemophilia,” 1.

⁴⁷ Andrew Pollack, “Hemophilia Patient or Drug Seller? Dual Role Creates Ethical Quandary,” *New York Times*, Jan 13, 2016, <https://www.nytimes.com/2016/01/14/business/hemophilia-patient-or-drug-seller-dual-role-creates-ethical-quandary.html>.

pharmaceutical companies. Even (or perhaps especially) for community members who try to navigate their various roles ethically, these dual loyalties can pull them in divergent directions. As one individual with hemophilia who works as a sales rep explained to me, “I kind of look forward to the day when I don’t have a conflict, when I can speak to this truth. Cause right now...I can’t be credible when I have this kind of conflict, when I’m drinking the Kool-Aid.”⁴⁸

Today, the line where community ends and industry begins is blurrier than ever. At a recent conference I attended, for instance, I learned that several huge Facebook groups for people with hemophilia were actually created by pharmaceutical representatives, who use them to find customers in their area and understand the community’s wants and needs. But even as this line between customer and seller has blurred, the various needs of both groups have remained separate and distinct. That divide rose to the surface of hemophilia politics most recently in 2020, when the FDA rejected BioMarin’s New Drug Application for a novel hemophilia gene therapy called Roctavian. Despite BioMarin’s promises that the product would durably raise factor levels in hemophilia patients, the FDA found that long-term follow-ups with study participants showed a steep drop-off.⁴⁹ When the Institute for Clinical and Economic Review (ICER) investigated the FDA’s decision, BioMarin submitted public comments arguing that the FDA placed too much weight on factor levels. Since the mutations that cause hemophilia can affect the potency of factor as well as its prevalence, they argued that the low bleed rates Roctavian patients experienced even with low factor levels might reflect increased factor

⁴⁸ Personal conversation.

⁴⁹ Ned Pagliarulo, “BioMarin tries to get hemophilia gene therapy back on track with positive data,” *BioPharma Dive*, January 11, 2021, <https://www.biopharmadive.com/news/biomarin-hemophilia-gene-therapy-phase-3-data/593118/>.

efficacy.⁵⁰ As HFA and NHF pointed out in their own comments to ICER, however, this claim “has no basis in fact. It has not been peer-reviewed and the sponsor has submitted no evidence to support it as a hypothesis.”⁵¹

Fortunately, parallel institutions in hemophilia took NHF and HFA’s side of the matter. ICER called BioMarin’s claim a “post hoc explanation for results based on a small number of data points,” and the FDA held firm in its rejection.⁵² Although unsuccessful, BioMarin’s attempts to create scientific fact in service of financial interests unmistakably call to mind factor companies and blood bankers who insisted that the risk of AIDS was “one in a million” even in the face of compelling evidence. When news of the FDA’s decision went public, the value of BioMarin stock fell by more than 35%.⁵³ People with hemophilia, on the other hand, were spared a substandard gene therapy that might have fallen short of BioMarin’s projections and prevented them from taking a future AAV-based therapy. Although the fact that the FDA prevented this outcome is certainly reassuring, the fact that they had to intervene in the first place is not.

In an era of safe recombinant factor and relatively expansive access to factor products, it’s easy for many members of the community to treat these misaligned interests as bygone of a darker age. Contrary to popular belief, however, new problems in hemophilia care like Roctavian demonstrate that these discrete incentives still matter. As such, the act of either remembering or

⁵⁰ D.M. Rind et. al., *Valoctocogene Roxaparvovec and Emicizumab for Hemophilia A: Effectiveness and Value; Final Report* (Boston, MA: Institute for Clinical and Economic Review, 2020), 36, Accessed April 17, 2021, https://icer.org/wp-content/uploads/2020/10/ICER_Hemophilia-A_Final-Report_112020.pdf/.

⁵¹ ICER, *Valoctocogene Roxaparvovec and Emicizumab for Hemophilia A: Effectiveness and Value; Response to Public Comments on Draft Evidence Report* (Boston, MA: Institute for Clinical and Economic Review, 2020), 6, Accessed April 17, 2021, https://34eyj51jerf417itp82ufdoe-wpengine.netdna-ssl.com/wp-content/uploads/2020/10/ICER_Hemophilia-A_Public-Comment-Responses_101620.pdf.

⁵² D.M. Rind et. al., “Valoctocogene Roxaparvovec and Emicizumab,” 36.

⁵³ Bill Alpert, “BioMarin Stock Slumps After FDA’s Surprise Rejection of a Hemophilia Gene Therapy,” *Barron’s*, August 19, 2020, <https://www.barrons.com/articles/biomarin-stock-valrox-fda-rejection-hemophilia-gene-therapy-51597853794>.

obscuring the hemophilia community's history is a deeply political one, with huge implications for the community's future. Although people with hemophilia have tried to memorialize and hold onto the community's history, their efforts have been undermined and complicated by a variety of other actors who also share an interest in how these events are remembered in the current day.

Because this history can undermine or shatter the illusion that people with hemophilia can trust the institutions that preside over their care, remembering or memorializing it in certain ways can be a transgressive act. In 2014, for instance, a gay man with hemophilia named Justin Levesque used his local chapter's annual meeting as a forum for a round table session about LBGTQ+ people in the community. Several members of the community criticized his decision in the aftermath of the meeting, including one unnamed person with hemophilia who asked Justin why he was "trying to bring AIDS back into our community."⁵⁴ The most obvious belief that these remarks convey is the bigoted conviction that gay men were responsible for the hemophilia community's suffering. Beneath that relatively unpopular belief, however, is a second, far more common conviction that AIDS is a thing of the past in the hemophilia community. Far from being "people who will Not Go Away," the thousands of people with hemophilia who contracted HIV through clotting factor have been half-erased from the community's understanding of itself.

This mass amnesia is only possible *because* clotting factor is now safe, and new generations of people with hemophilia no longer fear that their diagnosis will bring them into contact with HIV-contaminated product. But although hemophilia clotting factors have been purged of HIV, the impulses and incentives that led to their contamination in the first place are still distinctive features in American healthcare today. None of this, of course, means that this

⁵⁴ Justin Levesque, "Reflections on the LBGT Community," *HemoBlog*, March 20, 2016, <https://www.kelleycom.com/reflections-on-lgbt-community/>.

history will inevitably repeat itself. American people with hemophilia will probably never face a second iatrogenic epidemic, and may even live to see a cure within my lifetime. Even if the hemophilia community's road to a cure is a relatively smooth one, however, the fundamental problems in American healthcare that caused their mass infection will find new expressions in new crises. So long as it remains unchecked, the tendency to treat people with disabilities like commodities to be exploited will continue to produce outcomes like the hemophilia community's mass infection with HIV.

Epilogue

When I was in middle school, before I knew much about this history, I once attended a COTT open forum held at NHF's annual meeting. According to several of the organizers who spoke that day, COTT had seized the conference room for the event without NHF's knowledge or permission. Sitting in that room, I was struck by how few people my age had shown up. The older men with hemophilia, who I thought of as rarities in the community, had come out in force. I listened to them speak about the daily struggles of living with HIV, the sorrow and guilt of surviving when so many of their "blood brothers" had not, and the rage of knowing that those responsible had largely gotten off scot free. As I left that meeting, I re-entered the bright and cheery world of modern hemophilia shaken by what I had heard. Try as I might, I could not really comprehend the experiences of these survivors. I had no experience to compare to the trauma they spoke of, no frame of reference to even conceptualize the mass die-off that they had lived through. I wandered onto the annual meeting's luxurious show floor in a daze, completely ignoring the various booths where I could pick up free age-appropriate toys branded with the names of the corporations that oversaw the infection of the men I had just listened to.

A few years later, I tried to explain the COTT meeting to another friend of mine with hemophilia. Noticing the obvious agitation that the memory provoked in me, my friend tried to provide reassurance. He told me that his parents obviously appreciated the sacrifice of the COTT activists, but also that they thought COTT's politics were "stuck in the past." Implicit in this statement, of course, is the idea that these politics are no longer adequate for the current moment, as if they are relics of a bygone age that have outlived their purpose. I filed that idea away and noticed a similar rejection of the past a few years later, while talking to a fellow member of the local hemophilia community about the retirement of our chapter's old director. He explained that

the outgoing director had been exactly what the community needed during the epidemic, when people with hemophilia needed to organize and fight just to stay alive. Today, on the other hand, he explained that the chapter could use a new director with a fresh vision, who could draw in disengaged or new families and solicit charitable donations from investors.

To explain these moments of continuity and discontinuity, I turn to Lawrence Langer. In his work on memory and the Holocaust, Langer argues that survivors who deliberately relive a historical atrocity and non-survivors who reject these recollections are constants that transcend any one event. Rather than reading the inability of the survivor to move on as a symptom to be treated, Langer treats their testimonies of never-ending trauma as products of a sense of time that is durational rather than chronological. He writes that because historical atrocities continue to shape the present, survivors understand that “forgetting would be the ultimate desecration, a ‘cure’ the ultimate illusion.”¹ By proclaiming that the dismal past pervades the present, they create a view of reality which Langer calls “the alarmed vision,” which challenges the capacity of those who have not experienced such things to “‘normalize’ violence, disease, and other human abuses by placing them in the simple context of an agenda for improving the future.”²

Although a chronological recollection of hemophilia and AIDS is certainly more comforting than a durational one, an absolute rejection of the epidemic’s ongoing significance conceals more than it reveals. Contemplating this history of hemophilia and AIDS unnerves us, because it forces us to grapple with the fact that a medical system designed to offer relief to people with hemophilia ultimately became the delivery system for their deaths. It would be

¹ Lawrence Langer, “The Alarmed Vision: Social Suffering and Holocaust Atrocity,” *Daedalus* 125, no.1 (Winter, 1996), 55.

² Langer, “The Alarmed Vision,” 53.

easier to pretend that such things can be consigned to the past, and act as if we can condense the exploitation of the hemophilia community down to a specific moment in history. Rejecting that explanation leads us to the conclusion that the forces that produced this outcome still operate in American medicine today, which in turn suggests that our medical system has been infected with a spiritual disease that hijacks its infrastructure in order to turn it against the sick, the needy, and the vulnerable. As bleak as this perspective might seem, a bird's eye view of hemophilia history does suggest that the urge to treat vulnerable people like objects to be exploited is a constant in American medicine under capitalism. The callous indifference toward human life that led Hyland representatives to think of sales when Bob Massie thought of crippled joints and pain reared its head again in Cutter's decision to sell off its unscreened factor in foreign markets, and manifests itself today in new forms like the exorbitant costs of recombinant product and the underhanded direct-to-consumer sales tactics of the manufacturers.

Conceptualizing these things as manifestations of the same force should not lead us to despair, however. The American hemophilia community is no longer so vulnerable to the worst outcomes that can arise when health is treated as a commodity rather than a right, thanks to the tireless efforts of organizers who fought for justice and reform. Just as those community members joined with one another and even with those whom they shared almost nothing with besides an HIV diagnosis, so too can the modern American hemophilia community lend its resources and expertise to groups who face new iterations of these old abuses. This solidarity can only coalesce, however, if future generations of Americans with hemophilia confront their community's past and avoid falling into complacency. The true danger of forgetting this history, in other words, is not just that such things might happen to the hemophilia community again, but also that in our forgetfulness we might fail to recognize them when they befall someone else.

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